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Editorial: Into the Light

Megan A. Conway, RDS Managing Editor

My seven-year-old daughter had to do an oral poster presentation on a famous American. She chose Helen Keller, a choice guided in large part by me, always anxious to counter the social perspectives of disability as weakness and everyday things as miraculous already bombarding impressionable young minds in the first grade.

There is a girl with a disability I will call "Mary" in my daughter's class. Well, Mary is sort of in Susanna's class, which is to say Mary sometimes appears for lunchtime and special activities such as birthdays or field trips. When Mary does come to the classroom, she sits passively at her almost-always-empty desk with "Mary" printed at the top in large letters. Her name proclaims the truth of what is not apparent - that Mary is indeed a member of Room One. Mary is always accompanied by, or rather tethered to, a classroom aide. The aide's sole purpose seems to be to keep Mary from participating.

Case in point. I brought my hearing dog into the classroom to give my annual talk about "working dogs help people with disabilities and by the way people with disabilities are just like you." As expected, Mary was there, and as expected, she was sitting in the back of the room where she was least likely to cause a disturbance, or rather most likely to cause a disturbance because she couldn't hear what I was saying or see the pictures in the brightly illustrated children's book I was reading about "My Buddy the Service Dog."

After the story and a handful of eager questions from my audience such as, "What happens when Buddy has to go to the bathroom?" I sat with my dog while the children came up one by one to pet him. At last it was Mary's turn, and the aide manhandled her to the front of the room while Mary, not surprisingly given that her hand was being given as an offering to a large furry animal with sharp white teeth, was resisting. "No, no," wailed Mary, pulling away as the aide stood behind her, blocking her exit and shoving her towards me. "Hey," I said, "Let her go. She doesn't have to pet the dog. Step away aide! Mary can come on her own if she wants to."

The aide was in such shock she actually did what I said. She stepped back, ready to pounce on Mary if necessary, but releasing her arm from the death grip.

Mary got the most wonderful expression on her face. She stood there, surrounded by empty space, free, for a split second, to decide. And of course, as I had expected, she decided to come forward. She reached out her arm and she patted Presto, and then she gave me a great big smile, full of light, full of understanding. And then she was sucked back into the grip of the person meant to enable her.

But I was talking of Helen Keller, and my daughter's poster presentation. The assignment was to paste photos of the famous person on a large sheet of paper, along with captions describing why they were important. We had prepared for this assignment by reading from a biography of Helen and, since the biography was a little dry for a seven-year-old, watching a DVD of "The Miracle

Worker."

"What did you learn about Helen from watching the movie?" I prompted.
"She was deaf-blind."
"Okay, that's right, and what else?"
"She slapped people."
"What?"
"She slapped people. She knocked her teacher's tooth out. It was so funny!"

My first reaction was, "You can't put that in your report, that she slapped people! Surely there is something nicer than that you can say about Helen Keller!" So we wrote that Helen traveled a lot, and she was friends with Alexander Graham Bell, and she met Presidents, and she showed the world that deaf-blind people can do anything. I was incensed that Helen was always portrayed as a Savage who was rescued from darkness by the Savior, Annie Sullivan. Isn't that just the way of society, I fumed, idolizing someone because they became normal against the odds?

And that made me rethink my reaction to, "Helen Keller slapped people." What was slapping people but exerting her own sense of self, her right to want a doll, and to want it *now*. She was expressing her resistance against doing what she was told, doing what she did not understand. If Helen slapped Annie, it was because she was self-determined, because she had a sense of her own person as distinct from others and of herself as exerting control over her world. In bringing Helen "into the light" the essence of that self-determination was lost, at the expense of being able to express herself in a way that was acceptable to others.

One of the great conversations, if you will, about Helen Keller was her relationship with Annie. Because Helen relied on Annie for just about everything, the question arose of "who was Helen and who was Annie?" What of what Helen said was from Helen, and what was from Annie? My personal opinion is "what does it matter?" Together, they were two remarkable women. Apart from each other they were remarkable too. That was Helen the author, socialist, traveler, actor, dancer, speaker, thinker. But was she self-determined? Did she ever slap someone after she figured out that "water" was the stuff coming out of the well in the backyard? Not likely, because the mission of Annie, of Helen's parents, of the Perkins School for the Blind, of society, and of Helen herself, was for Helen to behave as if she were normal. That behavior involved giving herself over to the unseen hand of decorum. What part did "no" play in that equation?

Later that night, after my daughter was asleep, I took out the poster and wrote, "Helen slapped people," in small print, perhaps where the teacher would not see it, at the bottom of the page.

Introduction to the Special Issue: "Self-Determination" as a Social Construct: Cross-cultural Considerations

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This special issue of the *Review of Disability Studies* is meant to stimulate thinking and dialogue about how self-determination is conceived and promoted by and for people with disabilities, and how the concept and its application might be enhanced to better empower and improve the quality of life of people with disabilities around the world. We decided to devote time and effort to this topic because of our observations that self-determination as typically presented is not a good fit for cultural milieu in Hawaii and across the Pacific region. A likely reason for this lack of fit emerged as we read a large proportion of the many publications on self-determination and people with disabilities: the self-determination concept as typically defined is rooted in the individualistic values common to Western cultures, whereas most residents of Hawaii and other Pacific Islands come from collectivistic cultural backgrounds.

In line with the *Review of Disability Studies'* status as an international journal, our call for papers for the special issue sought analyses of self-determination from cross-cultural and international perspectives. This introduction is intended to help set the stage by briefly outlining how self-determination has come to be such a prominent topic in the disability-related literature, while also noting how this literature remains isolated from other potentially relevant literatures, such as that of social work.

Roots of the Focus on Self-determination for People with Disabilities

The concept of self-determination or personal autonomy can be identified in various philosophical tracts from across the ages. The historical roots of the current prominence of self-determination in disability-related fields have been traced by Frankland, Turnbull, Wehmeyer, and Blackmountain (2004). The earliest known English-language use of the term "self-determination" was in 1683 by John Locke in the context of philosophical debate over whether human behavior is the result of free will or pre-determination. Within the developing Western science of psychology in the late 1800s and early 1900s, the debate shifted from the role of God to the determination of behavior either by unconscious forces (e.g., Freud's id and superego) or the environmental contingencies of behaviorism. Beginning in the late 1930s, the development of personality psychology by Gordon Allport, Abraham Maslow, and others fostered theorizing about internal psychological causes of behavior. From this perspective individuals could be viewed as having psychological needs that they seek to meet through cognitive goal setting and decision making. Decades later, Deci and Ryan (1985) posited self-determination as an innate impulse shared by us all.

The idea that a people have the right to political self-determination is implicit in the 1776 Declaration of Independence for the United States. In 1918, US President Woodrow Wilson specified national self-determination as one of the principles that should guide world affairs after World War I. This principle has since been used to promote empowerment and rights for oppressed or marginalized groups of people through out the world. Nirje (1972) contended that

people with significant disabilities as a group have been denied their right to exercise personal self-determination. The disability rights movement that emerged into prominence during the 1970s in the US and elsewhere in the West included greater self-determination among its demands, as reflected in the rallying cry "nothing about us without us" (Fleischer & Zames, 2001). The success of this movement is reflected in the explicit recognition and promotion of self-determination in a broad range of legislation in numerous countries. Notable legislation in the US at the federal level includes the Rehabilitation Act Amendments of 1978 (which established Independent Living Centers), the Americans with Disabilities Act of 1990 (which created broad civil rights protections), the Individuals with Disabilities Education Act of 1990 (which promotes the involvement of students with disabilities in developing their own Individualized Education Plans and Individualized Transition Plans), and the Patient Self-Determination Act of 1990 (which requires that individuals receiving Medicare and Medicaid services be able to participate in and direct health care decisions that affect them).

The response of the US Department of Education's Office of Special Education and Rehabilitative Services (OSERS) to the disability rights movement included a self-determination initiative launched in 1988. This initiative created avenues for people with disabilities to participate at the policy making level, and also funded 26 projects to develop and demonstrate effective practices fostering self-determination for students with disabilities (Ward & Kohler, 1996). These projects were a major reason for the emergence during the 1990s of self-determination as an area of focus in the fields of special education and transition-to-adulthood (Frankland et al., 2004). Notably, the OSERS-funded projects represented an evolution in efforts to promote self-determination for people with disabilities, with the focus shifting from securing rights to self-determination to supporting individuals to be better able to exercise their rights and be more self-determined in their daily lives. The primary target populations for these efforts have been people with disabilities who may be at risk to be placed under the control of others. Examples include special education students and adults with intellectual or psychiatric disabilities who are subject to guardianship and possibly institutionalization.

Whose Life Is It?

Not surprisingly, the OSERS projects, which were all conducted in the US, identified personal attributes congruent with American individualism as essential components of self-determination. These attributes typically include a number of "self" words that are rarely associated with collectivistic values, such as self-advocacy, self-awareness, self-competence, self-direction, self-efficacy, self-evaluation, self-expression, self-realization, self-regulation, self-reliance, and self-responsibility. The approach taken in the numerous projects supported in the US by OSERS and other funders has generally been to identify specific attitudes, skills, and knowledge needed for self-determination and then provide training and opportunities for practice, with the aim of boosting the capacity of individuals to act as independently as possible to achieve their own goals.

However, questions have been raised about the utility and relevance of such approaches for people with collectivistic cultural backgrounds (Black & Leake, 2011). The self-determination literature tends to be based on a range of interrelated "constructs" commonly employed in Western psychology, such as intrinsic and extrinsic motivation, locus of control, and self-efficacy. By contrast, cross-cultural researchers often stress that their findings challenge

the original formulations of such constructs because they were developed by scholars who, as Markus and Kitayama (1991, p. 224) phrase it, used a "monocultural approach" rooted in the assumption that "the so-called Western view of the individual as an independent, self-contained, autonomous entity" corresponds to a universal human nature.

One construct at the heart of the contrast between individualism and collectivism is that of self-construal (how people perceive the relation of the self to others). In a widely cited article, Markus and Kitayama (1991) present a wealth of evidence that people in individualistic cultures view themselves as independent, with each person being a separate unit complete in itself, whereas in collectivistic cultures people consider themselves to be interdependent, that is, as part and parcel of a larger group. For example, people in traditional Pacific Island cultures have been described as developing "shared identities" as the result of "sharing food, water, land, spirits, knowledge, work, and social activities" (Linnekin & Poyer, 1990, p. 8). In other words, "The relationship defines the person, not vice-versa" (Lieber, 1990, p. 72). According to Imamoglu (2003), an inherent assumption of American-style independent self-construal is that when human development proceeds as it should, maturing people cast off their dependencies, bonds, and ties, and so become more and more independent from others – and the more independent, the higher the level of maturity. However, in a collectivistic culture, it is more likely that maturity is associated with increasing interdependence and orientation to achieving group goals.

The concept of "cultural competence" has been strongly promoted throughout the West in recent years as essential for the provision of effective educational, social, and medical services for the increasing numbers of residents of ethnic/racial minority heritage. However, Western professionals may face conundrums about what to do in the face of cross-cultural conflicts. The goals or paths chosen by their students or clients may clash with their own Western values. Alternatively, Western professionals may face the risk of being drawn into family conflicts, as often happens when parents try to maintain cultural traditions while their children adopt Western ways that give priority, for example, to self expression over obedience to authority (Sands & Wehmeyer, 1996). The example of independent living is often mentioned in the literature. Opportunities and supports for independent living have been among the major goals promoted by disability rights movements in the West (Fleischer & Zames, 2001). For many collectivistic cultures, however, multigenerational households are the norm and independent living is an alien concept that may not be readily accepted (Geenen, Powers, Vasquez, & Bersani, 2003).

The contrasts between individualism and collectivism with regard to self-determination are reflected in possible answers to the question, "Whose life is it?" The strong tendency in individualism is to respond that everyone's life is entirely their own, to make of it what they will, while in collectivism the response tends to focus on doing what's best for the group, which may well involve following the decisions of others (Shore, 1996).

Cross-cultural Perspectives on Self-determination in Social Work

The contrasts between individualism and collectivism raise the question of whether self-determination understood and promoted from an individualistic perspective is relevant or translatable for people from collectivistic cultures. Because this question is rarely addressed in the disability-related literature, we turned to the modern technique for finding answers, the Internet search.

It was surprising to discover that cross-cultural issues for self-determination are indeed a concern for a discipline that frequently touches the lives of people with disabilities, i.e., social work. It appears that despite having many common interests, the literatures of disability and social work scholars seldom make reference to each other. However, social work must surely offer useful insights into self-determination, given that the field adopted client self-determination as a guiding principle and goal nearly 50 years before Nirje identified it as an important issue for people with disabilities (Biestek & Gehrig, 1978). Later, during the 1950s, as Western-style social work practice began to be widely exported, scholarly debate burgeoned on how to best adapt social work to local cultural contexts while maintaining adherence to the principle of self-determination (Bar-On, 1999; Ejaz, 1991).

Bar-On (1999) provides a good overview of the complexities of the relevant issues for Africa, where there is generally a mismatch between the Christian individual-oriented values that launched the social work movementin the West and indigenous kinship-based collectivistic values. Of particular relevance to self-determination: every African kin group member "is an incumbent of a position with predetermined responsibilities towards every other member" (p. 13); maintaining social acceptability by fulfilling one's responsibilities is a pervasive concern; those in leadership positions are accorded great status and are expected to lead and others to follow; and consensus is highly valued (and people of subordinate status are unlikely to express disagreement).

Similar attributes characterize numerous cultures around the world, leading to significant differences compared to the West in how social workers interact with those they aim to support. In India, for example, many social workers set aside self-determination as a primary guiding value because their clients tend to resist the process of setting their own goals and developing action steps to address their problems. Instead, in line with longstanding relationships of dependency on and compliancy with people higher in the caste system, they tend to prefer being told what to do. Nonetheless, insightful social workers find ways to promote empowerment, for example, by using fatalistic attitudes as a vehicle for change, by supporting clients who believe in rebirth to build good *karma* in order to improve their situations in their next lives (Ejaz, 1999).

Ewalt and Mokuau (1995) also discuss the lack of relevancy of the American mainstream view of self-determination for many Native Hawaiians and other Pacific Islanders. They point out that for most professionals trained in the West, the family or society in general might be viewed as an obstacle to individual choice and self-determination. As a result, "rarely is contributing to the group's well-being considered integral to self-determination, and rarely is placing the group's well-being first seen as signifying maturity" (p. 169). Yet people who grow up in collectivistic cultures are likely to develop goals that are more group-oriented than self-oriented, so that "self-directedness may require a strengthening rather than a dissolution of the person's connection with and commitment to the group" (p. 170) – an assertion they point out is likely to seem "paradoxical" from the individualistic perspective.

In a similar vein, Gair, Miles, and Thomson (2005) argue that social work practice frequently fails Australia's Aboriginal population because it:

> "…often reflects values of individualism. These include the centrality of the individual as the focus of social work theory and practice, the focus on individual pathology, and

solutions that are defined by values of individual self-determination, self-help, and confidentiality. For indigenous peoples, a focus on individualism may exclude cultural and community values" (p. 182).

Furlong (2003) is one of a number of social work scholars who argue for a reconceptualization of self-determination based on cross-cultural considerations such as those noted above. He proposes that social workers should take a more flexible view of self-determination and support their clients to establish a balance between interdependence and autonomy that fits their particular situations. Falck (1988) asserts that a more accurate term would be *social self-determination*, because people everywhere set goals and make decisions in the context of webs of relationships among *social selves*. He points out that while it was laudable for social work to adopt the principle of self-determination to celebrate and support the integrity and autonomy of all human beings, it must be recognized that integrity and autonomy depend on and emerge from social relationships.

The Special Issue Articles

The first of the special issue articles, by Karen Applequist, Lissa Keegan, Jose Benitez, and Joshua Schwalbach, describes the ingredients of self-determination for an American Indian with learning disabilities who attended college far from his reservation home. The authors note that this individual enjoyed substantial advantages that included strong family support and an athletic scholarship accompanied by close supervision to keep him on track academically, raising questions about the prospects for self-determination for American Indians with disabilities who have few support resources. The next article, by Xiaoyi Hu and Susan Palmer, provides insight into self-determination in China through a case study of a young woman with hearing loss who graduated from college and established her own art studio. The article includes discussion of how the operationalization of self-determination may be impacted by the evolution of traditional Confucian values, such as growing acceptance of independent living. David Leake follows by outlining the case that the collectivistic value of interdependence is actually essential for self-determination in all cultures, because interdependent social relationships yield the social capital that most people need to achieve their self-determined goals. The logic parallels that of Falck (1988) noted above promoting the term *social self-determination*. Patricia Saleeby, writing from a public health/social work perspective, then discusses how self-determination and empowerment can be promoted for diverse people with disabilities through culturally tailored practices. She describes the examples of access to culturally diverse resources and community-based rehabilitation, which involves promoting and supporting group action by families, communities, and people with disabilities themselves. James Skouge and Mary Kelly describe how easy-to-use multimedia technologies can support the self-determination of young adults with significant disabilities of all cultural backgrounds by enabling them to communicate their strengths and "visualize" their preferred futures. They call on professionals and "critical friends" to re-tool their technology skills so that the people with disabilities they support can have more of a voice in the decisions that impact their lives. Finally, Angi Stone-MacDonald provides an in-depth review of the English-language literature concerning how disabilities are commonly conceived of and responded to in East Africa. An area of particular concern is that increasing migration from rural to urban areas tends to erode traditional protections for people with disabilities, making it ever more likely they will end up lacking social supports and among the poorest of the poor.

David Leake obtained both a PhD in anthropology and a Masters of Public Health at the University of Hawaii at Manoa, where he has worked with the Center on Disability Studies for over 20 years. He currently directs a federally-funded project demonstrating how youth with serious emotional/behavioral disorders can be empowered to envision and achieve their desired futures.

James Skouge is a traveler and teacher who has dedicated his career to "giving voice" to children, parents and teachers -- including persons with and without disabilities. Since 1992 he has promoted "digital storytelling" in Hawaii, American Samoa and Micronesia. Currently, Dr. Skouge is an associate professor in the Department of Special Education at the University of Hawaii.

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FORUM

Case Study on Transition: An American Indian Student with a Learning Disability

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Abstract: In this paper the results of a case study of an American Indian student with a learning disability who successfully transitioned to college will be presented. The student's attitude and behavior were shaped by his culture and his success was positively influenced by family, community, and supports from educational settings.

Key Words: transition, American Indian, self-determination

In the United States graduation from high school is marked by celebration for all students and heightened anticipation for many departing for college. Yet, not all American students have the same opportunity to be successful in higher education. American Indian undergraduates face more risk factors than their non-native counterparts; they are likely to be to single parents, to attend school part-time, or to need to work (Lee, Donlan, & Brown, 2010; US Department of Education, 1998).

American Indian adolescents with disabilities frequently encounter further difficulties when transitioning to college or university. High school students with disabilities in America receive special instruction and support under the Individuals with Disabilities Education Act (IDEA), but they no longer have the same support system when they enter college. Their success largely depends upon their ability to get needed assistance available at college. Wehmeyer (1999) recommends that high schools encourage self-determined behaviors that will enhance their ability to be successful adults.

Field, Martin, Miller, Ward, and Wehmeyer (1998) defined self-determination as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations, together with a belief of oneself as capable and effective are essential to self-determination" (p. 2). Wehmeyer (1999) draws on this definition to highlight the four functional characteristics of self-determination: a) person acts autonomously, b) behaviors are self-regulated, c) the person initiates and responds to the event(s) in a psychologically-empowered manner, and d) the person reacts in a self-realizing manner (p. 56). Although these four characteristics can be influenced by "age, opportunity, capacity, and [current] circumstances" (Wehmeyer, 1999, p. 57), all four must be present for behavior to be considered self-determined.

With the emphasis on autonomous behavior and individual goals, this definition of self-determination is seen as "Westernized," making it difficult to apply to collectivist cultures, where independence outside of the group is not sought. Many students from other countries share this collectivist orientation and may face similar concerns with this definition. Frankland, Turnbull, Wehmeyer, and Blackmountain (2004) conclude that many of the principles of self-determination are consonant with the Dine (Navajo - one of the larger American Indian tribes in the US) culture, but note the emphasis is on interdependence rather than independence. However,

generalizing these conclusions to other tribes would be inadvisable, and to date there have not been any published studies of this nature.

The purpose of this study was to explore those factors that contributed to the successful transition to college of an American Indian student who has been diagnosed as having a Learning Disability (a psychological processing disorder affecting spoken or written language, including mathematics). Accordingly, we focused on intrinsic (motivations and attitudes of the focal person and other significant persons) and extrinsic (familial, cultural, environmental, and educational) influences impacting his self-determination and success in transition.

Context of the Study

The focal person was born and raised in a very rural community on reservation lands in the southwestern region of the United States. Children from his community are able to attend elementary and high school in nearby communities on the reservation and are no longer sent to boarding schools. However, opportunities to attend college close to the reservation are very limited, forcing adolescents to leave their communities.

Tippeconnic (2011) presents a framework for the values of American Indians emphasizing what he refers to as the 4 Rs - relationships, responsibility, reciprocity, and redistribution representing a collectivist orientation. Limb, Hodge and Panos (2008) juxtapose American Indian values and those of mainstream American society highlighting those of collectivist and individualistic orientations respectively. The American Indian culture traditionally values respecting and caring for others, patience, and humility while mainstream American culture values individualism, competitiveness, and attention-seeking behaviors.

Methods

This case study was designed to explore in-depth those factors contributing to an individual's successful transition and was part of a larger national study focused on transition of culturally and linguistically diverse students with disabilities. The focal person was identified as successful as he was close to completing his college education. After obtaining his consent, he was asked to identify those individuals who he felt impacted him in positive ways prior to and during his transition who would be interviewed. General guidelines identifying topical areas of emphasis (e.g., barriers, supports, significant people, role of family and culture) aligned with the research questions were reviewed in preparation for all interviews. For purposes of continuity, all interviews were conducted by one member of the research team. A second team member regularly met with the primary interviewer as interviews were conducted to discuss emerging themes. Audiotapes of the interviews were transcribed for purposes of analysis.

During the initial coding process, QDA Miner (a computerized qualitative data analysis program) was used. Operational code categories (LeCompte & Schensul, 1999, p. 57) were developed based on the original purpose of the case study. These categories included perceived barriers to successful transition, significant persons, behaviors and attitudes of significant persons, behaviors and characteristics of the focal person, and other influences. Each of these code categories had between 4 and 11 codes, for a total of 39 codes. Although we started with

this top-down approach (LeCompte & Schensul, 1999), additional codes within the above categories were added as patterns emerged from the data.

An axial coding (Strauss & Corbin, 2007) approach was used to further investigate two codes that yielded a large amount of coding. Once the coding structure was finalized one member of the research team coded all of the transcripts while another coded 25% of them to establish inter-rater reliability. Initial inter-rater reliability was 96% and increased to 100% after the raters discussed and negotiated discrepant codes. The research team, comprised of two special educators, a counselor and a graduate student in student affairs, met to review and discuss the patterns identified during coding and agreed on six emergent themes from the data.

Findings

Duane's Story

Duane was identified as learning disabled when he was in elementary school and struggled with reading and math throughout his academic career. He disliked elementary and middle school; but flourished in high school, when he joined the track team. Running is a long-standing tradition in many American Indian tribes (e.g., Gilbert, 2010; Nabokov, 1981) and many members of Duane's family are runners. He excelled at running, winning many races, and he was offered a number of athletic scholarships.

Once he decided he wanted to go to college, he worked harder in all of his high school classes. He chose to be fully included in high school, and benefited from further tutoring made available to all students. He was allowed to use a calculator in math classes and took full advantage of the dictionary. Through a transition class, he learned what to expect in college, and visited college campuses. He ultimately decided to attend a small community college over 300 miles from home where few American Indian students were enrolled. While the transition was difficult for him, he felt the smaller school was preferable so he could get to know his instructors better than at a large university. After completing his associate degree, he transferred to a much larger public university closer to his home.

Because tribal traditions are integral to his daily life, he felt very isolated when he first went to college and he created audiotapes of native songs that helped him feel more connected. He missed the ceremonies and festivities that are conducted year round in his community, and described these experiences as making him feel "pure" again. The university's Native American Student Services supports students academically, socially and culturally. Duane availed himself of the academic supports, but felt the other services were tailored for students from different tribes. When asked if he experienced discrimination in college because of his learning disability, Duane indicated that was not the case. The only discrimination he described was sensing that some classmates felt he would not do his fair share on a small group assignment based on his ethnicity, not his disability.

Multiple Perspectives of Duane

Interviews were conducted with Duane (on two separate occasions) and four individuals identified as playing important roles in his successful transition, including two cross-country

coaches, a reading professor, and the disability advisor from his community college. In this section we will highlight the recurring themes across the interviews.

Duane's Self-Determination is Rooted in his Tribal Belief System

American Indian ideals of perseverance and diligence are inherent in Duane's statements and actions and fostered and sustained his self-determination. He did not allow his learning disability to dissuade him from his goals.

> "Knowing your boundaries, your potential, he just gets everything right. He didn't bite off more than he could chew, he just did a little bit at a time and did a good job at what he is doing and I think that doing it that way, he became a lot more confident in his abilities as a student and as an athlete and as a person" (Coach).

His motivation to attend college was rooted in the need to give back to his people. He pursued a degree in education so that he could return to the reservation and teach at the high school. Once he set his goal, he worked diligently to reach it. "There is something there with that kid that says, if you push that kid in the right direction, he will take it from there" (Coach).

> "As long as you are willing to do what it takes and stay up late working and running on the weekends, all that is part of being successful, just working hard at it. I guess that is my whole main goal here, to show people that you can make it" (Duane).

The disability advisor at the community college described Duane's work ethic:

> "He just seemed to stick with it, his dedication to his studies again, for his age, stood out and with the additional load of having track, it makes it even harder. You combine that with a learning disability it is even harder, so his stick-to-it-iveness was excellent, his dedication."

Role of Family was Critical to his Success

Members of his family provided a foundation for a successful transition. "A lot of people come up to me and they would give me encouragement to stay in school" (Duane). His mother, in particular, was extremely supportive of Duane as he notes, "She was always telling me 'don't be afraid to ask questions; there's nothing wrong with asking questions.'" Duane's parents emphasized the importance of considering college. "They always kind of talked to us about how education is important – part of today's society and that's what you need, a good education" (Duane).

Duane's college track coach admired the support that his family gave him:

> "His parents are great people, they supported him in anything he wanted to do and everything he wanted to do and my part is just in addition to what the parents had already done, so I just kind of picked it up from there, just support him… I think that he could just pick up the phone and call his parents and they would do everything in their power to make sure that whatever was going on was taken care of and so I give them a lot of credit, just this family support."

Duane also felt comfortable asking his older brother for guidance. "And he's like 'I mean if you have any questions and just, just call and ask me I'm more than willing to help you'" (Duane). In addition, Duane received emotional and monetary support from his grandparents: "Yeah, my grandparents are real supportive…Like when I tell them like yeah, I'm gonna be goin' to college and they would be more happy and excited for us" (Duane).

Identity Focused on Running, Minimizing any Stigmatism from his Disability

The overarching theme that emerges from the interviews is that Duane is a well-respected athlete, and that despite struggling in school because of his learning disability, is seen as a successful student. Running is not only part of his cultural heritage; it helped him to establish an identity other than 'the student with a learning disability.'" Ever since I started to excel in running, that's when the whole teasing of the learning disability went down" (Duane). However, he also expressed acceptance of his learning disability, referring to his high school experience:

> "I mean they would say stuff to me about it, but I'd be like, 'Yeah, I mean I am, there's nothing I could do about it.' …I think that's where I developed that whole sense of not being ashamed of my learning disability" (Duane).

Supports Offered through Athletic Programs Mitigated his Disability

As a student athlete Duane was eligible for access to scholarships, lessening the financial burden. "Getting serious about college happened my junior year when I started getting scholarship letters" (Duane). Moreover, he also received additional tutoring given to athletes and mentoring from his coaches that enabled him to keep his grades up so he could continue to compete. "I don't think he'd get here without running" (College professor). In many ways, the supports and mentoring he received because he was a competitive athlete mitigated the impact of his learning disability on his education. "For Duane to be invited into this program, we would have to see a lot of talent in him, with the learning disability" (Coach). He continued:

> "The average Joe Student that shows up, not many people care about him like they do the athletes. I mean I watched him literally every day he was here, but you know the average Joe Smith who shows up, nobody know he is there unless he tells someone basically" (Coach).

Internal Conflict between Cultural Expectations and Pursuit of Excellence

Excelling at running, however, also caused internal conflict for Duane, in being recognized as an individual in a culture that values humility and collectivism:

> "I was like I want to go on…it did occur to me a couple times that I just wanted to stop with everything I am doing and just live life, equal, I mean I am equal, I am not saying I am above but I mean as far as they [team and classmates] are concerned they think that I am above and whatnot" (Duane).

Duane struggled with the decision to leave his community:

> "I mean, the cultural thing it really does affect what we want to do in life… for cultural reasons you know we have to come back because we have duties to perform and if we don't do these duties then the ceremonies will die so you have to kind of think about that, whether you want to put our culture at risk of losing it just because I want to go around here in [large city off reservation], just because I want to go overseas to go run or something like that and you really have to take stuff like that into consideration" (Duane).

Duane's culture also impacted his college and career path:

> "Like my first choice was as a physical therapist like sports doctor. So later on I kind of figured out just thinking about it about how much criticism I would get from the people saying that I shouldn't be doing this because I'm not one of the people that is naturally gifted with that ability to help people out" (Duane).

Interconnectedness of Support Network

It was readily apparent that there was a willingness of the various key people in Duane's life to work together to support him. His coach in high school would contact his teacher if there were problems with his assignments. His mother established contact and relationships with his teachers and counselors in high school and his coaches and disability counselor at the community college. The counselor at the community college worked closely with his coaches and his teachers to monitor his progress and make sure he was getting the help he needed. His extended family supported him, and checked in with each other on his progress.

Discussion

Duane's success can be attributed to a complex array of intrinsic and extrinsic factors. His attitude and behavior embodied the four functional characteristics of self-determination (Wehmeyer, 1999) and were influenced by his tribal belief system. Moreover, his talent as a runner was a distinct advantage to him throughout the transition process. He would not have been successful without important support from family, community, and key staff from both high school and college. The importance of self-determination and a broad range of supports will be explored further.

Self-Determination

The four essential characteristics of self-determination were earlier identified as: a) person acted autonomously, b) behaviors are self-regulated, c) the person initiated and responded to the event(s) in a psychologically-empowered manner, and d) the person reacted in a self-realizing manner (Wehmeyer, 1999). The process of individuation was clearly reflected in this case study. Duane was presented with many opportunities to make choices and he made those decisions on this own. For example, he chose to be fully included in high school rather than be placed in the resource room. Duane made the decision to become an athlete in high school knowing that he possessed innate talent, even though he struggled with his unintended sports star status. He established goals for himself and sought the support he needed to meet those goals. His goals reflect an understanding of his role in the community, and his personal strengths and limitations. He constantly struggled to achieve the desired harmony and his place within his

family and community. Duane accepted his learning disability and understood that he needed to work more diligently than his classmates to be successful in school.

In Duane's case, his cultural beliefs and practices were powerful influences on his self-determination. His overarching goal of becoming a teacher so that he could give back to his tribe in a meaningful way sustained him throughout his studies in college. As is the case with the Dine (Frankland et al., 2004), the construct of self-determination is fairly compatible with his culture, with some alteration. Emphasis on the clan, family, and community, above the individual, influences how the process of self-determination evolves.

System of Support

Duane drew enormous strength from his family and his community, enabling him to develop more confidence in navigating the transition from high school to college. His mother, in particular, provided guidance and support. All of his immediate and extended family were proud of his accomplishments and gave him moral support. He established a mentoring relationship with his high school coach, who is also a member of his tribe, that continued after he graduated. Having a mentor who shares the same cultural values and experiences has been found to be much more effective (Campbell & Campbell, 2007). Teachers, coaches and support personnel in both high school and college mentored him in significant ways. His success and those of other culturally and linguistically diverse students with disabilities can often be attributed largely to mentoring (Leake, Burgstahler & Izzo, 2011).

Because the enrollment was quite small, faculty and staff at the community college knew students on a personal level and created a web of support that students attending larger state universities do not have. For example, Duane felt comfortable enough with his reading professor that he would frequently drop by her office just to visit but this type of relationship occurs less frequently in larger schools.

Duane's experience is characterized by many positive or protective factors that other American Indian students with learning disabilities may not have. His athleticism facilitated his transition, enabling him to become more goal directed and focused on his running and studies. He did not experience the risk factors (delayed enrollment, part-time attendance, financial problems, having dependents, being a single parent, working full time or completing a GED) many American Indian students may have as undergraduates (U.S. Department of Education, 1998, p. 89).

Yet, this case study reveals the types of supports that can be helpful to other American Indian students with disabilities. Until Duane shifted his focus to his strength (running) he struggled in school. The structure and continuity of the supports coordinated by his coaches were instrumental in facilitating his success both racing and academically. While the intensity of these supports are not available to most students, effort should be made to create or replicate these types of opportunities for other American Indian students with learning disabilities. Figure 1 depicts the positive influences that enabled Duane to be successful. Duane was supported by his family and culture, but also directly influenced by the relationship between his Coach and Disability Resources Counselor (the person overseeing educational accommodations for students

with disabilities) at the community college, who monitored his grades and progress. This mentoring/monitoring provided a safety net that gave Duane the freedom to grow as a student.

Figure 2 is a model proposed for American Indian students with disabilities who are not athletes. While the proposed model would apply to all students with disabilities, it has specific relevance to students who are American Indian transitioning from native communities who face unique challenges (Lee, Donlan, & Brown, 2010). One of the key contributors to Duane's success was the connectedness between his support networks (family/culture, disability resources, and the athletic program), with his coach being his mentor. Since not all students have access to the mentoring relationship of a coach, the proposed model substitutes three currently existing systems, Student Services (offering career counseling, and academic advisement), Counseling Services (offering individual and group counseling to address personal issues) and Disability Resources (assisting with academic accommodations). We believe that if these three systems work closely together to support a student, they can recreate the mentoring/monitoring relationship of a coach. This also brings up one of the striking differences between Duane's two experiences in higher education. In addition to the coach, one of the services provided by Disability Resources at the community college was a counselor/advisor, who helped him plan his schedule, recommended courses/professors and monitored his progress. He did not have this same depth of service from the larger university. However, we would argue that having a "point person" who is able to coordinate the services available to the student from the three systems is something that universities should consider.

Presently, at many schools, although each system is aware of what the others offer, there is not active coordination between them. Thus, students with disabilities, who may have difficulty negotiating service systems, may be left on their own to seek out services from each independent system. The services offered by the different systems are rich and varied: Student Services offers individualized academic tutoring and connections to additional academic support as well as skill-building in reading, note-taking, research and project planning, test preparation, and test-taking strategies to all students. Disability Resources helps students access classroom material through accommodations. Counseling Services are available for all students, but are unlikely to be oriented to developing the self-advocacy skills particularly needed by students with disabilities.

Implications for Practice

Although Duane's athletic ability opened doors for him that would not have opened for other American Indian students with disabilities, there are nonetheless some very important lessons to be learned from his experience. One lesson is that teachers and other staff who have successfully completed a college education off reservation and are working in native communities must recognize their important role as mentors to students who are transitioning; they can help demystify the process.

At the high school level, special education personnel and transition specialists must continue to promote self-advocacy skills and self-determination in the context of person-centered planning. A key elements of person-centered planning is the identification of strengths on which to build. While Duane's athletic talent was an obvious strength for him, other students may struggle to identify their strengths or interests. The literature suggests that professionals

frequently operate from a deficit-based model rather than a strengths-based one (Smith & Nevin, 2005). Beyond making a paradigm shift, there are several strategies high school and college personnel can use. Students should be encouraged to view their culture as a resource and positive influence in their lives. Various tools, such as interest inventories, can be used to gather information that will help students learn more about their interests. Students should be actively engaged in the transition planning process, identifying their goals, so that they can assume more responsibility for decisions when they begin college.

Duane chose to begin his college education at a small community college, and it may be desirable for American Indian students with disabilities to start out in a community college where they would have a greater chance of getting individual attention. In Duane's case a system was in place at the community college for student athletes so that they could be academically successful. American Indian students with disabilities should be familiar with the range of supports available to them at any institution and should know how to access them. New student orientation programs foster the acclimation of students with disabilities to the university by ensuring they are aware of the various programs and supports available on campus.

If collaboration between Student Services, Disability Resources and Counseling Services is enhanced, it should be possible to provide all students with disabilities with systems of support that mimic those available for many student athletes. Such a system might provide an assigned advisor who assists the student in planning their schedule, offers advice as to which professors would best meet their learning style, monitors the student's progress, and coordinates services between Student Services, Disability Resources and Counseling Services. In this scenario, the advisor is acting as the student's "coach."

In cases where the student is from an American Indian background, there should also be coordination between these three systems and programs for American Indian students, if available. Improved coordination among relevant systems and programs will help ensure that students with disabilities do not "fall through the cracks." As universities strive to achieve higher rates of recruitment and retention, these supports should be part of the marketing strategy so that students with disabilities can make informed decisions about which institution to attend.

Recognition of the role of family members in a student's life is vital and must be respected throughout the transition process. Duane's parents were actively involved in his education and were welcomed to campus. Helping students with issues around identity and career paths should be sensitive to the collectivist orientation and cultural norms. Programs developed for American Indian students can play a significant role in helping students bridge the cultural gap between home and school. These programs should be designed for all students representing different tribes who have different tribal beliefs and customs. Indigenous students with disabilities residing in other countries would benefit from a similar model that is culturally responsive.

Future research should include participants from other tribes as there can be significant differences between tribes. A better understanding of the ways high schools and colleges can coordinate their programs and processes in a manner that will benefit American Indian students with disabilities is critical in promoting their academic success.

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Figure 1: College Influences on Duane.

Duane's attitudes and behaviors were heavily influenced by family and culture. The athletic program coordinated closely with Disability Resources.

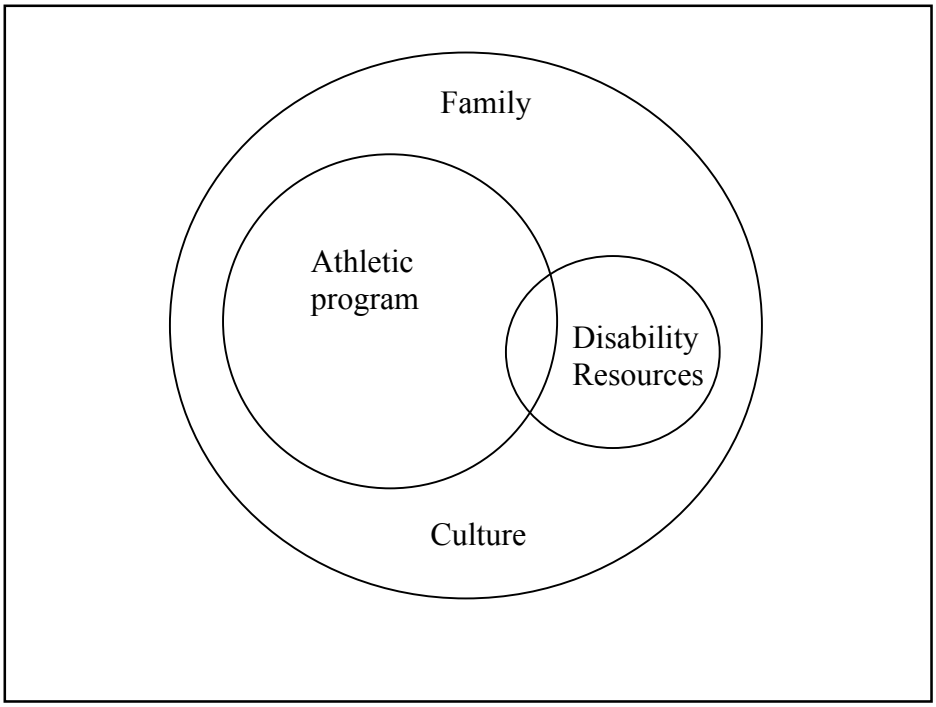
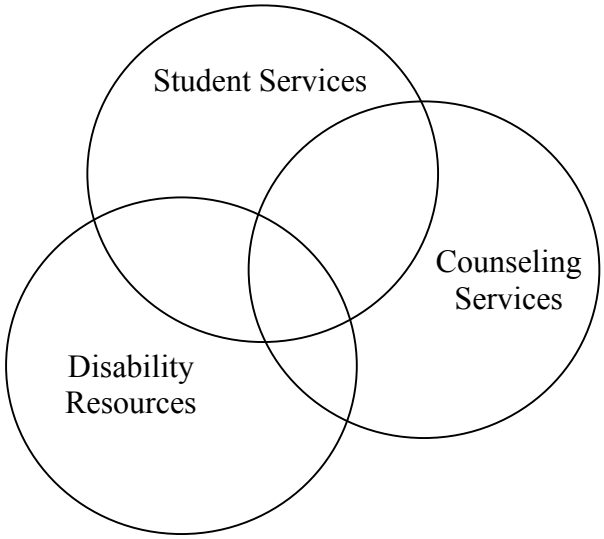


Figure 2: Recommended College Supports for American Indian Students with Disabilities.

American Indian students with disabilities benefit from a coordinated approach from all three programs.



Self-Determination within the Chinese Culture: Examining Cultural Values

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Abstract: The importance of fostering and enhancing the self-determination of children and youth with disabilities has received increased attention over the past 20 years. Little research, however, has focused on exploring the intersection of cultural values and self-determination. This qualitative study examined the application of the self-determination construct from a Chinese girl with a hearing impairment. Data were collected via a focus group and semi-structured interviews with Ying and her family members, teacher, employer, and friends. Qualitative data analysis identified eight overarching categories, which were subsumed under three thematic areas: (a) operationalization of self-determination in Chinese culture, (b) facilitators in promoting self-determination, and (c) barriers to promoting self-determination. Implications within the Chinese culture for developing self-determination strategies and future research to support Chinese youth with disabilities are discussed.

Key Words: Chinese, culture, hearing impairment

Since the 1990s, self-determination for students with disabilities has been a major focus of research in the field of special education (Karvonen, Test, Wood, Browder, & Algozzine, 2004). Although numerous definitions of self-determination have been offered in the literature over the past 10 years, this article will refer to the recent work of Wehmeyer (2005) as defining this construct. Self-determined behavior, according to Wehmeyer (2005) refers to "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life", (p. 117). In western culture, self-determination has been shown as a means to achieve the desired outcomes of self-sufficiency and independence. However, these initiatives have primarily focused on self-determination from the perspective of Western values and beliefs, such as independence and personal control (Leake & Boone, 2007; Shogren & Turnbull, 2006; Turnbull & Turnbull, 1996). As Turnbull and Turnbull (2001) stated, "many definitions of self-determination are rooted primarily in an Anglo European ethnic orientation" (p.57).

While researchers have long recognized the need for promoting self-determination in a greater variety of cultural contexts (Wehmeyer, 1997), very little research has focused on exploring the intersection of cultural values and self-determination. A few discussions of this issue include Frankland, Turnbull, Wehmeyer, and Blackmountain's (2004) look at the relation of theory and practice of self-determination to Diné culture; Trainor's (2005) qualitative study on self-determination perceptions and behaviors of African, Hispanic, and White male adolescents with learning disabilities; and Leake and Boone's (2007) look at cultural influences on self-determination in comparing the views of youth, parents, and teachers representing a range of ethnicities. One consistent finding of these studies is that although component elements of self-determined behavior and perception relate closely to culture and beliefs of people from varying cultural identities, people in other cultures expressed or operationalized self-determined behavior

differently. Moreover, individual variability within ethnic groups indicated the critical need for addressing individualization when promoting self-determined behaviors (Wehmeyer, 2011).

This case study profiles Ying, a 21-year-old girl with hearing impairment, from the People's Republic of China. Ying provides an example of someone from another culture who is self-determined: having struggled and accomplished her goal of obtaining a university degree, making profits from her own art design studio, and living independently. Ying was an actor for the China Disabled People's Performing Art Troupe (CDPPAT) and attended Avalokitesvara Bodhisattva, a dance performance presented at the 2008 Beijing Olympic Games Opening Ceremony. Indeed, Ying is an actor in her own life instead of being acted upon by others because she knows what she does well and where she needs assistance. These distinguishing characteristics lead to the research question that guided this study: How do Chinese cultural beliefs and traditions shape the ability of Ying to develop effective self-determination strategies? How is the self-determination construct best operationalized in Chinese? Due to the lack of empirical studies regarding the implementation of self-determination in China, the primary purpose of this study was to investigate the operationalization of self-determination in China, where most children with disabilities are segregated in special schools and taken care of within the family. In addition, implications for developing self-determination strategies and suggestions for future research related to Chinese youth with disabilities will be explored.

Method

This study employed a case-study methodology, using a multiple-incident single-subject study design. A case study approach supports the researcher to ask "how?" or "why?" when there is limited control over events, especially in a real-life setting with a relatively underdeveloped theoretical base or where complex observational tasks are involved (Yin, 2002).

Participants

Ying is of middle Northern descent and became deaf due to a medical accident when she was five years old. She used both Chinese Sign Language and oral speech to communicate. When she worked on her bachelor's degree in Art Design, she did part-time fashion modeling. Currently, she is self-employed and living independently in Beijing. A total of 12 participants engaged in this study, including Ying, her parents (hearing parents), teachers, employers, and friends.

Data Collection

A team of two researchers collected data using multiple sources and modes of evidence for analysis to ensure the validity of the case study (Yin, 2002). Data collection included: (a) document analysis, (b) individual interviews with participants, (c) a focus group, and (d) home visit observation.

We first collected news reports about Ying, essays and poems from Ying's online blog, as well as evaluation and IEP data. In addition, semi-structured open-ended individual interviews with Ying, friends and superiors from CDPPAT were conducted. Insights of Ying's high school special education teacher and family members (i.e., parents and maternal grandparents) were obtained in a focus group. The interviews questions and focus group discussion guides were

developed on the basis of frank and open discussions with participants previously, focusing on broad aspects of self-determined behaviors, such as decisions made to live independently and be self-employed, perceptions of efficacy, and self-directed learning skills. Finally, we used an observation guide and detailed field notes recording data about the context of the home visit, interactions between the interviewer and the family members, and noted specific self-determined behaviors observed.

Data Analysis

A variety of tools for data analysis were utilized for this study including (a) transcripts, (b) field notes, (c) documents, and (d) summary sheets. We employed an analytic induction approach to conduct ethnographic analysis that allowed us to identify the recurring themes and cultural elements (Merriam, 1998). As coding occurred, we drafted memos, identifying consistent and poignant findings. More specifically, we adopted a form of pattern matching as analytic technique in which we reviewed all the data (Yin, 2002). We then formed our initial explanation about the operationalization of self-determination in a Chinese cultural context. A thorough search of the data was then conducted during follow-up discussions with participants in which we checked our initial reactions and looked for negative evidence and alternative explanations. We then moved to a more deductive mode of thinking and analyzed the data and modified the proposed themes as well as explanations. Finally, the findings were sent to participants for review and feedback.

Trustworthiness of the Data

In an effort to establish reliability and validity of the data, three strategies were used. First, data triangulation was achieved by utilizing multiple sources including interviews, focus groups, field notes, documents, and summary sheets from interviews. Second, we conducted member checks and peer examination which allowed both participants and members of the research team to "comment on the findings as they emerged" (Merriam, 1998, p. 204). Finally, trustworthiness was established by prolonged engagement with participants in the data analysis to generate themes and show participants transcripts and interpretations for their review and responses (Creswell, 2007).

Results

The transcripts and document analysis address a wide range of topics. However, the purpose of this paper is specifically on the analysis with regard to participants' perceptions of self-determination in a Chinese cultural context. These themes generated were: (1) the operationalization of self-determination in Chinese culture, (2) facilitators in promoting self-determination, and (3) barriers to promoting self-determination.

Theme 1: Operationalization of Self-Determination in Chinese Culture

The first theme that emerged is the participants' perception of self-determination. As one predominant Chinese value, the family unit is regarded as the essential foundation for achieving self-determination. Next, coexistence of independence and interdependence gives insights into explaining the impact of western culture on Chinese families. Finally, indirect communication style reveals a unique value addressing the way that Chinese facilitate self-determination.

Family Unit

The first obvious emergent category, family unit, plays a critical role in promoting self-determination. An important Chinese cultural ideology is Confucianism, which stresses one unique family value system that would put family above their individual and personal needs (Chan & Lee, 2004). As Ying described herself on her blog:

> "If there is no support and love from my dear family members, there will be no Ying as you see today. You may think that owning a studio or performing around the world is important to me, but actually, family is the most important as well as my central focus of my life. I am a part of my family and I do things for my family."

As the most significant virtue to be held in Chinese culture, filial piety was manifested at Ying's family. According to Ying's mother:

> "In our family, Ying's father and I set a good example to show reverence and obedience to [Ying's] grandparents. In return, Ying does a great job in resolving our concerns and needs by performing her duties outside homes and brings a good name to the whole family. [So] I believe Ying takes our family's need into careful consideration whenever she makes important decisions."

On the other hand, under the effect of modern individualism, a new set of family values has changed family attitudes towards Ying. For example, Ying's parents need to call her first for a home visit for the sake of privacy. Her mother further explained, "At first, [when] she refused to give me keys [to her home], I felt humiliated. But then, I got to know it was respect."

Coexistence of Interdependence and Independence

China is commonly viewed as emphasizing group-focused values, or interdependence, whereas Western societies are thought to focus on individualistic values, such as autonomy and self-reliance. Chinese parents are expected to place less emphasis on independence, and to discourage such things as the expression of aggression and impulsive behaviors by youth. Consequently, Chinese education is focused on socialization of youth as being prepared more extensively to serve societal rather than individual goals. This was evident when Ying described her life at CDPPAT:

> "All the performers, [including] me, of course, felt excited and proud to perform at Athens on the behalf of more than twenty million deaf Chinese…. Although I sacrificed a lot: [I gave up pursuing] master degree, it is worthwhile…. Also, all the other members sacrificed too. Avalokitesvara Bodhisattva is a team work, if one got distracted and made wrong gesture, the audience will notice for sure."

On the other hand, Ying did demonstrate some dimensions of independence. A powerful example is independent living. Ying's moving out to live on her own was highly valued in Ying's family. Ying's friends also expressed strong wishes too: "She bravely, happily, and successfully face the challenges of living independently. We want to move out of our families, but they have legitimate concerns and fears; even feel a little bit shame…. But with time and patience, most things can be done."

In addition to living independently, Ying's autonomy was illustrated by the poem *Bird* she published on the Newsletter of People with Hearing Impairment in 2000: "Here I stopped for a while/ I got my dream realized/ I fly again /To the new, brilliant dreams/ It's my life!" Additionally, Ying's autonomy was highly recognized by her superior at CDPPAT, "Ying distinguished others for her self-reliant behaviors. She studied English whenever she got some time during our intensified training... She knows what she wants, and how to manage her time to get it."

Indirect Communication Style

Within efforts to promote self-determination in western contexts, there is an emphasis on the development of skills that depend on effective communication skills: the ability to self-advocate, express choice and decision, as well as build up relationships (Wehmeyer, 2007). The communication patterns of Chinese serve to reinforce traditional cultural values and beliefs (Chan & Lee, 2004). In accordance with predominant values of maintaining harmony and face saving, Chinese employ an implicit, nonverbal communication style dependent on the receiver's ability to correctly interpret the others' genuine intention, opinions, or feelings. According to Ying:

> "In those days at CDPPAT I get to know many new faces. At first, I felt a little bit nervous because of my unclear speech. Then I found actually a significant amount of communication was conveyed through nonverbal behaviors, [like] eye contact, smiling, gestures, especially gestures…. I am good at reading body languages. I suddenly found that I can take advantage of it to set up friendship. Even now, I can easily understand my clients' intentions as well as make appropriate decisions."

Ying's teacher also expressed her expectation of indirect communication style on students when she infused decision-making strategies into her curriculum:

> "I hope that students to express their decisions more in an implicit way so as not to dispute their parents or future employers. There exist some examples that my radical students failed to persuade their parents to pursue their goals after graduation and broke up their previous harmonious relationship."

Theme 2: Facilitators to Promote Self-Determination

Close examination of facilitating factors to promote self-determination was the second theme that emerged from the transcript. Participants' views were expressed in two subthemes: (a) family harmony and (b) focus on moral development.

Family Harmony

Because Chinese people value family as the central focus of an individual's life, the foundation to generate obligation and loyalty, build trust and interdependence, they like to devote more energy to maintaining their families and as a result, they tend to get more support and attention from their families (Chan & Lee, 2004). At Ying's parents' home, there is a Chinese calligraphy scroll painting telling that "If the family lives in harmony, all affairs will prosper." Family

harmony was essential to develop choice-making and problem solving capacity, especially at Ying's early age, as Ying's mother elaborated:

> "At her third grade, she began oral speech training but found huge difficulties. One day when I got back, I saw her squatting at the gate and crying. She told me she could not speak out several vowels. I began to realize the seriousness of this issue. Then the whole family and Ying talked about it several times…. She wanted to continue oral training instead of wholly depending on sign language. We helped her figure out her strength that she had already learned for about half a year and could speak out some vowels…. [We] set up a schedule and each of us worked with Ying on practicing every day. Three months later, Ying succeeded in pronouncing those vowels!"

In addition, focusing on choice-making and problem solving skills in a harmonious family environment supported the development of effective decision-making skills later in her life. In her blog, Ying described her decisions to be self-employed as "greatly supported by the consistent encouragement and assistance from family members."

Focus on Moral Development

Chinese culture is oriented toward morality which focuses on cultivating human nature by conforming to sets of moral principles and fostering virtues such as self-sacrifice, perseverance, modesty and humility (Chan & Lee; 2004). Consequently, moral education has been prioritized as one essential component of special education. Ying's IEP suggested curricula on moral development had been provided to Ying from elementary school to university in differentiated levels. Ying's teacher further elaborated on how she addressed self-identity in her teaching: "I try to convince them that they do not have a tattoo on their forehead. Students cannot ignore their disabilities, but can pursue what they like and what they can do."

Theme 3: Barriers to Promoting Self-Determination

Obstacles to promoting self-determination is the third theme, which could be further categorized into the following three subthemes: (a) child bearing beliefs and practice, (b) emphasis on academic performance, and (c) negative assumptions on disability.

Child-Rearing Beliefs and Practices

Typically, a Chinese family is characterized by well-defined, highly interdependent roles within a highly cohesive, patriarchal, hierarchical and vertical structure (Chan & Lee, 2004). Even though China is undergoing rapid social change and westernization, the Confucian thought of strict family hierarchy still remains one of the most important moral standards that guide the decision-making behaviors of family members (Goodwin & Tang, 1996). In general, parental authority and power are highly emphasized. Children, in turn, are regarded as extensions of their parents, being unquestioningly obedient or subordinated to any decision that authority figures made in the family, especially at early age (McHale, Rao, & Krasnow, 2000). These cultural values were explicitly evident at Ying's family and limited Ying's opportunities to practice self-determination:

> "I never dare to say no or question any decision of my grandfather and father even though I disagree. They usually have the final say on many important issues…. They don't want me to sign very often because they feel being deaf is a kind of shame. So they made me wear gloves every day although I did not like it!"

In addition to the emphasis on child obedience, due to the One Child policy which has been in effect for twenty years, Chinese children are portrayed as "little emperors" always treasured, protected, and overly indulged within warm and secure family environment. Such indulgence results in lack of self-confidence, inappropriate self-awareness, poor social communication and strong self-centeredness when they are challenged by new tasks or environment. Ying's teacher recalled Ying demonstrating strong cooperative skills, high confidence in learning, and willingness to try new tasks which were in sharp contrast to other students who always attribute grades as the result of good or bad luck, or unfairness of teachers' judgment. The teacher described the current profile of high school students with disabilities:

> "In addition to pushing responsibilities to others, [nowadays] they are lacking enough confidence and courage to be the owners of their lives. I try to engage them in the curriculum design and encourage them to speak out their future goals. But [they] told me: 'I have no ideas. My mom will arrange everything for me. I don't need think about it'!"

Emphasis on Academic Performance

Traditional cultural factors can also impact the way that families, teachers and children value education (Gu, 2006). Chinese families uphold this cultural value that their primary responsibility is to provide their children with the best education. For instance, in order to prepare for the entrance exam to the higher institution, Ying's family moved to Beijing and spent heavily on a house near the institution. In turn, successful academic achievement is the greatest tribute children or youth can bestow on their family, as Ying further noted:

> "My performance on the entrance exam had a direct impact on my whole life. I cannot imagine what if I did not get high scores on the entrance exam, if so, I would let my parents down and lose their face. As for the reasons to apply for college, I thought it was for meeting family expectations, please them, not actually for me."

Furthermore, according to Confucian teachings, "Children are ingrained with a lifelong respect for knowledge, wisdom, intelligence, and love of learning" (Chan & Lee, 2004, p.253); teachers put priority on an outcome of knowledge transmission above strategies related to self development, including problem-solving skills, self-learning capacity, and creativity (Gu, 2006). As one teacher spoke from the bottom of her heart:

> "Nowadays, there are no more jobs assigned from the local labor department available anymore… So we have all recognized the importance to begin self-determination oriented instruction…[Also] students would more love to make friends without disabilities and involve in the mainstream society. However, the starting point of self-determination begins with teachers' attitudes, beliefs, and actions. [On the other hand], we already have huge pressure to make sure [they] prepare well for the exams. I really have no idea to do whether students have the time and energy to take these self-

determination skills training seriously enough because [it] is not a compulsive part of exams."

Negative Perceptions of Disability.

Traditional cultural beliefs can also influence people's attitudes towards disability (Chen, Brodwin, Cardoso, & Chan, 2002). Chubon (1992) pointed out negative social attitudes towards disability can result in "invisible barriers" to enjoying a high quality of life. Leung (1993) stated that people's attitudes are viewed as a significant factor in determining the life experiences and help-seeking behaviors of people with disabilities. For example, Ying's grandmother believes in karma, a belief in that Ying's hearing impairment represent a divine punishment from immoral behavior or wrong-doing committed by her parents or ancestors. Although attitudes toward people with disabilities are improving in recent years, the cultural stigma and discriminatory beliefs towards persons with disabilities still exists. When Ying performed at Athens Special Olympics, what her family got from relatives and neighbors was not applause and blessings, but complete surprise and suspicion. Ying's teacher spoke of inclusive education approach as a solution to change public attitudes toward disabilities. She believed that specialized curriculum on self-determination can not truly benefit students with disabilities. Meanwhile, Ying and her friends suggested awareness of disability as the first step to understanding and acceptance. This reflects a lack of social awareness that must be addressed by the coordinated effort of both the public and people with disabilities.

Discussion

The present study was conducted as an initial attempt to explore various facets of the operationalization of the self-determination construct within a Chinese cultural context. In a purposeful effort to promote self-determination among students with disabilities and give insight to professionals, facilitating factors and the impediments to achieving those goals, and the role of culture in fostering self-determination on students with disabilities are distilled from data.

There may be a view held by some that collectivist cultures, such as Asian cultures are counter to self-determination, since a sense of self is always comprehended in the relationship with others (Browder, Wood, Test, Karvonen, & Algozzine, 2001). However, coexistence of both independent and interdependent behaviors found in this case study, as well as participants' openness to new ideas and status based on individual achievement rather than on one's ascribed traditional kinship ties, demonstrated an individualistic focus. Our findings also suggest that autonomous functioning is not incompatible with an interdependent orientation. It is due to the tremendous impact of Western thought and beliefs on new generations during the past three decades after the adoption of the reform and open policy (Vernoff & Seybolt, 2007). As Gu stated: "The present Chinese culture is undoubtedly a mixture of Western and Oriental, traditional and modern, Marxist and non-Marxist and socialist and capitalist features." (Gu, 1996, p.11). Evidence of both orientations in our findings provides insights on how Chinese cultural models of the self and the other and the relationship between self and others when promoting self-determined behaviors among students with disabilities. More specifically, Chinese traditional values and Western values can be found and may vary on the individual level, therefore, it is important to consider that, when making decisions; Chinese students may make different decisions from either family's needs or their own.

The findings of this study were in line with the ecological model of self-determination proposed by Abery & Stancliffe (2003a), which emphasizes self-determination occurs as a result of ongoing interplay, across the life span, between individuals and their multiple environments. However, this model was developed within dominant American cultural settings (Abery & Stancliffe, 2003b). This study addresses the significance for understanding the ecological theory of self-determination from other cultural backgrounds. Clearly, challenges to promote self-determination in Chinese cultural underscores the need to include the impact of cultural identity into this model in order to expand the cultural components embedded in the operationalization of self-determination.

The development of a basis for understanding the impact of Chinese culture on self-determination is a critical starting point for China. Efforts to develop self-determination for students with disabilities have largely been ignored in Chinese disability-related fields, especially in special education. This case study found that negative views and humanitarian aid towards individuals with disabilities marked by humanistic values are prevalent in China and constitute the basis of policies and practices in current special education system. Therefore, at a more basic level, public awareness of disability is the first step. Furthermore, segregated special education schools and classrooms impede the development of self-determination skills. The voices of the special education teacher who call for inclusive education suggest the need to provide students with disabilities more freedom and opportunities to be with students without disabilities.

Our findings also call attention to the operationalization of self-determination through behaviors that reflect the embedded Chinese cultural values, which may not be identical to those found in western societies. For example, Ying's self-help and self-reliance were emphasized. However, the primary purpose of the emphasis was not to pursue personal goals, but rather to contribute to the honor of the whole family and the well-being of the society. Therefore, autonomy may not be so distinct from conformity and the ways in which autonomy is expressed may be different. This result is similar to the meaning of autonomy found in Diné culture (Frankland, Turnbull, & Blackmountain, 2004). As Ewalt and Mokau (1995) suggest: "It is necessary to appreciate how contributions to group interest may ultimately strengthen the person as well" (p.169).

Implications

Limitations of the Study

Limitations of the study, however, should be noted. First, because we deliberately used just one participant who demonstrated excellent self-determination capacities, and came from a large city, our conclusions may not be generalizable to the wider population as well as be representative of all youth of disabilities, especially intellectual or other cognitive disabilities which further impact success in any culture. Moreover, selection of Ying as a key informant provides insights into factors contributing to her successful self-determined life, which present a less than typical life story in China. In addition, we only included one representative of the school system we hoped to influence: a special education teacher. Voices from other members such as school administrative staff and speech therapist may reflect more diverse characteristics of the Chinese culture on current special education system.

Implications for Practice

Since 2004, the special education field in China has undergone a significant paradigm shift that involves rethinking ways to provide vocational training and practical curriculum addressing the needs, preferences and involvement of students with disabilities, instead of only focusing on academic courses. Some initiatives on decision-making training and self-directed learning strategies have been taken in special education schools from major cities (Li & Zhang, 2008). Therefore, students' and families' responses to self-determination teaching are of significant value for educators. On the basis of the findings from the present study, we offer the following practical recommendations to Chinese special educators to approach the obstacles found in the findings when they design and teach the component behaviors of self-determination.

The first key consideration for educators is to recognize that promoting self-determination requires respecting student's choices and preferences, not achieving adult outcomes that are valued by their families or someone else. Similar to the findings of Leake & Boone (2007), honoring student's values by adhering to the principle of individualization can assist professionals in understanding what constitutes desirable adult outcomes. For instance, some youth may choose to live independently, while others may continue living in the same household with their parents and other family members to maintain family ties.

Second, educators should actively collaborate with families to develop students' self-determination in home settings. For instance, when students make decisions, these students may place the family's needs and happiness above their own. What's more, educators should be aware that families may have differentiated commitments to Chinese traditional values as well as family's unique values, which can influence their children's desires on actualizing self-determined behaviors (Leake & Boone, 2007). In addition, it is important for teachers to point out how self-determined young people can bring honor to their families because of their greater potentialities for success.

Third, educators need to provide opportunities to develop students' social relationship with others, especially peers without disabilities. As indicated from the findings, students with disabilities desire to develop social skills with other students who are not disabled. . In current segregated special classrooms, direct instruction on self-determination is not sufficient because students need to generalize their skills into real-life settings. One important recommendation, which is already being implemented, is to infuse components of self-determination training into current special education curriculum and moral development courses.

Finally, educators should encourage students with disabilities to be involved in educational planning and IEP meetings. The findings of this study suggest students' lack of involvement in curricular plan and IEP development. It is partly due to the indulgent-permissive parenting style and indirect communication styles, which may impede students' speaking out about their needs and enumerating their strengths (Bao & Zhang, 2005). Although educators should address academic performance, the infusion of components of self-determination into existing courses would provide students ongoing opportunities to reflect on their goals, identify their needs, and see the connections between learning and goal attainment.

Implications to Further Research

First, the findings of this study may encourage researchers to assume that self-determination is not only applicable in western cultural contexts, and not limited to only a few component elements such as choice-making or problem solving. This study calls for further examination of the operationalization of the self-determination construct within cultures that may differ in focus from western cultural emphasis. Therefore, more research from cross-cultural perspectives is needed to study the interaction of self-determination and cultures, especially those with a mixture of various traditional and modern values. Indeed, as a moderating variable in efforts to promote self-determination, culture, is not static, but fluid and dynamic (Chan & Lee, 2004).

Second, because cultural beliefs and behaviors are continuously influenced by new information and in constant adaptation by a changing environment, an individual's goals and values for self-determination are not transmitted across generations unchanged (Trainor, 2005). Therefore, it is also our obligation to interpret the new cultural values on various components of self-determination in order to understand the role of self-determination in numerous cultures. In particular, the findings of the study underscore the need to explore the environmental impact of the macro system variables (e.g., social and cultural values) and micro system variables (e.g., individual, family) as well as their interaction on self-determination (Hoffman & Field, 1995).

In addition, further research could call for selection of a case or cases exemplifying opposite characteristics from Ying, with particular attention to whether the same themes (or their opposites: e.g., disharmonious family) contribute to the lack of success or cases with other typical disabilities, including persons with cognitive disabilities or developmental disabilities.

Last but not least, perspectives, attitudes, and expectations from various stakeholders on promoting self-determined behaviors, such as family members, professionals, and employers need to be explored so as to expand or modify the components of self-determination. More important, the findings of this study call for further investigation on how parents contribute to self-determination of their children because families can be both facilitators and inhibitors to promoting self-determination.

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Self-Determination Requires Social Capital, Not Just Skills and Knowledge

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Abstract: Curricula and programs designed to support students with disabilities to gain greater self-determination are typically rooted in individualistic values stressing independence and self-reliance. However, it can be cogently argued that the collectivistic value of interdependence is actually essential for self-determination in all cultures because interdependent social relationships yield the social capital that most people need to achieve their self-determined goals. Interdependent relationships should therefore be given greater weight and attention in self-determination theory and practice.

Key Words: social capital, individualism, collectivism

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Introduction

"The reason some of us are self-determined is that we are in interpersonal and social structural relationships that empower us" (Sprague & Hayes, 2000, p. 681).

Self-determination has emerged as a major focus of interest in disability-related fields, as reflected in numerous journal articles and conference presentations on the topic and in the many self-determination programs and curricula developed for students with disabilities (Browder, Wood, Test, Karvonen, & Algozzine, 2001). These initiatives generally have a narrow focus on specific aspects of self-determination theory or practice, which in turn are typically rooted in the values and assumptions of Western individualism. The aim of this article is to promote a broader understanding of self-determination by examining it from a cross-cultural perspective.

The results of cross-cultural research on a wide range of topics are frequently analyzed in terms of the individualistic-collectivistic continuum of values. The individualistic worldview is commonly presented as deeming people to be discrete entities who, as they transition to adulthood, should move from dependence to independence and self-reliance. In contrast, the collectivistic worldview considers people to be woven into the fabric of groups (e.g, family, village, tribe), and as they transition to adulthood they should move from dependence to interdependence. Individualism is often described as stressing individual rights, pursuing personal interests, setting and achieving personal goals, and being true to one's own values and beliefs, and collectivism as stressing obligations that go along with one's group roles, being an interdependent member of a group, working with others to achieve group success, and adhering to the group's traditional values (Triandis, 1995; Yamauchi, 1998).

The concept of self-determination is a product of Western thought, so it naturally has an individualistic flavor that directs attention to the personal characteristics of individuals and away from the possible influences of their social contexts and relationships. This individualistic orientation is clearly reflected in this synthesis of common themes found across numerous

definitions in the special education literature by Field, Martin, Miller, Ward and Wehmeyer (1998):

> "Self-determination is a combination of skills, knowledge, and beliefs that enable a person to engage in goal directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults." (p. 2)

However, this perspective seems to overlook the essential importance of interdependent social relationships that potentially yield *social capital*, defined by Kanazawa and Savage (2009) as follows:

> *"Capital* is any resource that helps individuals produce or achieve some goal. *Social capital* inheres in relationships between individuals, just as *physical capital* inheres in physical objects and *human capital* inheres in humans. Thus social capital is any resource that inheres in relationships between individuals that helps them produce or achieve some goal" (p. 873).

This definition's focus on goals is congruent with standard conceptions of self-determination, which typically highlight goal setting and striving as prototypical self-determined activities. A substantial body of research confirms that people who are strongly socially connected are indeed more likely to achieve their goals and be "housed, healthy, hired and happy" than those who are not (Woolcock, 2001, p. 12). Practices that support people with disabilities to expand their social networks – such as person-centered planning that creates "circles of friends" or "circles of support" – are increasingly recognized as effective ways to build social capital that in turn fosters both greater self-determination and improved quality of life (Condeluci, Ledbetter, Ortman, Fromknecht, & DeFries, 2008).

I was led to delve into various literatures touching on self-determination as a result of my involvement in a research project on cultural influences on self-determination funded by the US Department of Education's Office of Special Education Programs for the period 2002-2006. Our grant application made the case that because virtually all efforts to promote self-determination are guided by individualistic values, these efforts may not be as relevant or effective as they could be for people with disabilities from collectivistic cultural backgrounds (Bui & Turnbull, 2003; Greene & Nefsky, 1999; Leake & Black, 2005a, 2005b; Luft, 2001; Trainor, 2005; Wilder, Ashbaker, Obiakor, & Rotz, 2006). This is a matter of concern for many educators and service providers because people of ethnic/racial minority heritage, many of whom have collectivistic cultural backgrounds, are an increasing proportion of populations throughout the West. In the US, for example, people of ethnic/racial minority heritage are projected to increase from about a third of the population to over half by 2050 (US Census Bureau, 2008).

Our primary data source was 20 focus groups conducted in Hawaii and Washington, DC with a total of 121 participants, 32.2% of whom were Caucasian and 67.8% of whom were of ethnic/racial minority heritage, representing all the major categories used by the US Census Bureau (Asian, Black, Hispanic, and Pacific Islander). Groups consisted of youth with

emotional/behavioral disorders (55 participants), parents of such youth (39 participants), or special educators with experience teaching such youth (27 participants). As described by Leake and Boone (2007), a variety of cultural themes relevant to self-determination emerged in analysis of focus group transcripts, and these themes were generally understandable in terms of the contrast between individualistic and collectivistic values. For example, it was found that decision-making about further education in ethnic/racial minority families with traditional orientations is often parent-driven with youth giving priority to supporting their families, while in mainstream White families decision-making tends to be more in the hands of youth who are encouraged to follow their own dreams.

Interdependence and Self-Determination

If Westerners honestly consider the factors that have allowed them to choose and strive for their presumably self-determined goals, they will almost certainly conclude that other people in their lives have provided essential supports. This is in fact widely recognized, as reflected in the standard practice of people who receive awards or set athletic records acknowledging the contributions of their friends, relatives, teammates, and other supporters. Significantly, there is evidence that when Westerners remember or describe their experiences, they might well acknowledge the critical role of help from others while still considering themselves as meeting the individualistic ideal of being independent and self-sufficient. For example, White and Groves (1997) interviewed 80 elderly individuals in Queensland, Australia and found that they typically explained that they relied on helping networks in order to maintain their treasured independent lifestyles. These authors note that:

> "…what has begun to emerge in the research literature is that successful interdependent relationships (with family, friends, neighbours and the local community) tend to respect and reinforce independence as a cherished component of an older person's self-image. According to Linder-Pelz (1991), the ideal image of the aged should be of healthy independence, supported by family, friends and community – in essence, interdependence" (p. 85).

An important theme that emerged in this qualitative research was that of reciprocity: the elderly interviewees indicated that they did not consider themselves to be dependent (a particularly dreaded state from an individualistic perspective) as long as they could reciprocate in some way when receiving needed help from others. Based on this and other research, White and Groves (1997) conclude that "where assistance is mediated and perceived as being given within a reciprocal relationship or agreement, the perceived level of dependency is reduced and an increased sense of personal self-determination and perceived independence is reported" (p. 88).

The individualistic values and sense of being independent units typical of Westerners are likely to bias their understandings of social processes in particular ways. For example, research indicates that Westerners are more susceptible than people raised in collectivistic cultures to the "self-enhancement bias", which is the highlighting of personal factors (such as intelligence, creativity, talent, or effort) when explaining success while downplaying supports from the social environment (Kitayama, Markus, Matsumoto, & Norasakkunkit, 1997). The revealing findings of research conducted by Groysberg, Lee, and colleagues (Groysberg, Lee, & Nanda, 2008; Groysberg, Lee, & Abrahams, 2009) puncture what they call "the myth of the lone star". They

followed 1,053 highly ranked financial analysts over a period of nine years in New York City, and found that they almost always suffered a decrease in performance if they were hired away by other firms, and the overall performance of the recruiting firms tended to suffer as well. A primary reason for such outcomes was found to be that moving analysts left behind crucial supportive relationships with fellow workers. They typically required at least two years to establish well-functioning teams at their new workplaces, although most never managed to regain their previous performance levels that had made them "stars".

The point that individuals depend on social capital to succeed in their endeavors is encapsulated in the convoy model of social relationships with respect to the life course (Carstensen, 1992). According to this model, developed by Kahn and Antonucci (1980), people tend to move through life with a relatively stable "convoy" of friends and relatives who provide each other with emotional and instrumental supports, a sense of group and personal identity, and a comforting feeling of continuity.

The concept of social capital links the disparate messages above about the elderly in Australia, financial analysts in New York City, and "convoys" of friends and relatives. As indicated by Kanazawa and Savage's (2009) definition quoted in the introductory section, social capital is a product of social relationships and is needed by people to achieve most of their individual or group goals. For example, research indicates that between 40-70% of employees in the general population find their jobs through social contacts (Parris & Granger, 2008). Potts (2005) argues that social capital is even more important for job seekers with disabilities, who are more likely to need mentoring and other supports in finding suitable jobs and maintaining employment. Parris and Granger (2008) therefore recommend that in addition to the usual focus on building vocational skills during the transition-to-adulthood phase, "focus must also be given to relationship building skills, as well as encouraging relationships formed between students with disabilities and community members" (p. 168).

Implications for Self-determination Theory

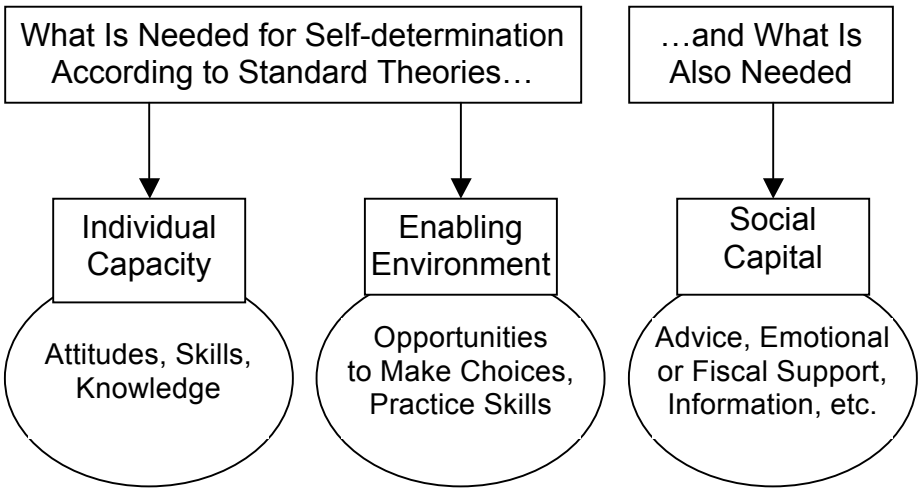
One message that clearly emerges from the above discussion is that *interdependence* is an essential concept that should be addressed in a comprehensive theory of self-determination. In this regard, Deci and Ryan's (1985) self-determination theory does posit "relatedness" as one of three universal needs that must be met for people to experience self-determination. However, they do not explicitly connect relatedness with either interdependence or the social capital produced by having positive social relationships. Rather, they view such relationships as important for self-determination because they promote psychological well-being and a secure emotional base from which people naturally develop intrinsic motivation.

Three other theories of self-determination (all with a disability focus) are presented in Wehmeyer, Abery, Mithaug and Stancliffe (2003), and to varying degrees each theory also recognizes the salience of interdependence. However, it appears that these theories touch on interdependence in order to address a conceptual problem that often arises when self-determination is promoted for people with intellectual and other significant disabilities. Self-determination from an individualistic perspective tends to be equated with independent decision-making and action, but people with intellectual disabilities, for example, tend to lack the capacity to act independently with regard to many important life choices. Self-determination thus needs to

be theoretically recast as a process in which people with significant disabilities take an active role but also rely on and heed the advice and judgments of people they know and trust, just as adults without disabilities may entrust their retirement savings to presumed financial experts. For people with intellectual disabilities, "shared or collaborative decision-making" represents an alternative interdependent avenue to self-determination (Abery & Stancliffe, 2003, p. 45).

Although the self-determination theories referenced above acknowledge relatedness and interdependence, they do not seem to take the next step of explicitly recognizing that all of us, with and without disabilities, require the social capital produced by interdependent social relationships for our self-determination. Abery and Stancliffe (2003) do begin to approach this conclusion in noting that "social skills" contribute to self-determination by promoting supportive social relationships and allowing greater independence in the community, but they give no greater weight to social skills than the other seven skills they deem to be essential self-determination competencies. By contrast, Sprague and Hayes (2000) perceptively argue that self-determination and the closely related concept of empowerment are too often conceived as composed of traits (such as specific skills) of autonomous individuals rather than as properties emerging from relationships. Indeed, all the self-determination theories I have come across in the disability literature specify sets of traits or capacities that should be targeted for training in order to foster self-determination, and also state that an enabling social environment is required. However, the case I have been making indicates that a third component, namely social capital, is essential (see Figure 1).

Figure 1. Standard theories of self-determination identify individual capacity and an enabling social environment as key ingredients but neglect the importance of interdependent social relationships.



Implications for Self-Determination Practice

Theory, practice, and research guide and inform each other as they shift over time. The current state of self-determination practice is to a large extent an outcome of the US Office of Special Education and Rehabilitative Services's self-determination initiative launched in 1988. This initiative funded projects around the United States that sought to identify the component parts of self-determination and to develop and test ways to teach and support people with disabilities to gain those components. No one can doubt that this investment in self-determination has yielded returns many times over. There has been a flowering of self-determination curricula and programs that have touched a great many people with disabilities of all ages, which in turn has helped raised awareness of self-determination not only in the US but in countries around the world (Ward & Kohler, 1996).

However, these curricula and programs have sometimes been critiqued for their narrow focus on teaching specific skills – a focus that is to be expected given that they are designed for use in schools and other institutions with training missions. Virtually all curricula and programs seek to meet modern teaching standards by breaking "self-determination" down into its presumed skill and knowledge components and using formal assessments to track student progress (Turnbull et al., 1996). According to Mithaug (1996), this approach may not be effective for many students because "the perceptions, knowledge, and abilities comprising the process of self-determination are not easily deconstructed or task-analyzed, taught separately, and then reconstructed into the functional process of self-determination" (p. 150). Turnbull et al. (1996) criticize this "unidimensional emphasis on individual skills" for its lack of attention to addressing environmental barriers and collectivistic values like interdependence. In line with the individualistic ideal of people as independent and self-sufficient, the overall orientation is to give people the necessary skills and knowledge, after which they are more or less set loose to function as best they can, hopefully in an independent and self-sufficient way.

The limitations of the skills training approach are particularly evident if we seek practices that can meet the theoretical proposition that social capital is essential for self-determination. The general neglect of social relationships is reflected in research on effective self-determination practices in special education by Karvonen, Test, Wood, Browder, and Algozzine (2004). They conducted literature reviews, meta-analyses, and site visits to model programs that use "promising practices". The strategies common to each of the model programs were found to include: (1) curricula to teach self-determination skills; (2) teaching and coaching students to increase their involvement in developing their own individualized education plans; and (3) noninstructional practices, such as discussing with students the pros and cons of their different choice options. However, none of the programs is described as having a focus on social relationship building.

For students with disabilities who have difficulty developing and maintaining social relationships, the natural response from the standard skills training perspective is training in social skills. Unfortunately, most meta-analyses of the relevant research indicate that such training for students with disabilities tends to generate only small gains, if any, in social skills that generalize to real-world settings (Gresham, Sugai, & Horner, 2001; Quinn, Kavale, Mathur, Rutherford, & Forness, 1999), although a recent meta-analysis did find more positive results (Cook et al., 2008). In addition, social skills training might be critiqued on the same basis that vocational skills training in segregated settings for people with significant disabilities often has been: their progress in mastering skills may be so incremental, and unlikely to generalize to real-

world settings, that they may never be judged ready for competitive employment, so supported employment is a more appropriate intervention (e.g., Wehman & Moon, 1988). Similarly, social skills training for many individuals may not lead to enhanced social relationships, so interventions that might be termed "supported friendships" might be more effective.

The idea of "supported friendships" is inherent in the well-established practice of person-centered planning that was developed particularly for people with intellectual and other significant disabilities. In this approach, friends, relatives, advocates, and service providers are brought together to support them to identify and achieve their own goals and to "be there" for them over the long term by creating committed "circles of friends" or "circles of support" (Cotton et al., 1992; Mount, 1997; Rainforth, York, & Macdonald, 1997). Person-centered planning is typically used with people with significant disabilities of adolescent age and older, but the same principles appear applicable for those with less serious disabilities and of younger age.

A notable development for practice is the promotion of the concept of social capital itself as a way to substantially improve services for people with significant disabilities (Bates & Davis, 2004; Cocks, 2007; Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008; Whitley & McKenzie, 2005). A relatively recent special issue of the *Journal of Vocational Rehabilitation* was devoted to social capital, with guest editors Condeluci et al. (2008) asserting that social capital has the potential to "re-invent rehabilitation", making this "one of the most important issues of the Journal" published to date (p. 139). Several of the articles describe how particular organizations have revamped their policies and practices to ensure a consistent focus on building social capital for those they serve, both by fostering relationships with other people in the community and by promoting greater social inclusion of all people with disabilities (Flaherty, 2008; Parris & Granger, 2008; Zimmerman, 2008). Schools and other public and private agencies should likewise consider making the building of social capital a guiding value.

Implications for Self-Determination Research

Condelluci et al. (2008) also note: "It is amazing that, as of this writing, there has been no major study or effort, either at the university or foundation level, that has scientifically studied social capital and disability" (p. 137). An initiative to fund and coordinate research on social capital seems to be called for, as a next step building on the research base developed for self-determination. In this regard it appears that rich sources of potential data are being created by relatives, friends, self-advocates, and professionals who recognize that the social networks of many people with disabilities are constrained by stigmatization and social exclusion. They are responding with countless informal and formal efforts to promote the social acceptance and inclusion of people with disabilities by organizing, for example, anti-stigma campaigns and inclusive sports leagues, clubs, proms, and summer camps. These efforts are described in the newsletters and websites of numerous disability-related organizations and increasingly in the broader media, as compiled for example in the Council for Exceptional Children's daily on-line newsletter, *CEC SmartBrief* (http://www.smartbrief.com/news/cec/). Research is needed to identify the specific attributes of such initiatives that might be effective in increasing the scope and quality of social networks, and in turn to examine whether enhanced social networks in fact lead to greater self-determination, which is the underlying hypothesis of this article.

David Leake obtained both a PhD in anthropology and a Masters of Public Health at the University of Hawaii at Manoa, where he has worked with the Center on Disability Studies for over 20 years. He currently directs a federally-funded project demonstrating how youth with serious emotional/behavioral disorders can be empowered to envision and achieve their desired futures.

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The Need for Culturally Appropriate Strategies in Promoting Self-Determination Among Individuals with Disabilities

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Abstract: While strategies promoting self-determination have been effective in the United States and other Westernized countries, these identical approaches and "best practices" are not necessarily effective in cultures that do not embrace the same individualistic values. In these settings and situations, culturally appropriate approaches are necessary to engage these individuals with disabilities and their families while promoting similar principles underlying self-determination, empowerment, social justice, and rights. This article provides an overview of some traditional strategies promoting self-determination and/or empowerment and then discusses how these are not always useful in practicing with culturally diverse population groups even in the United States. Alternative approaches are described such as the access to culturally diverse resources and community-based rehabilitation that adhere to specific cultural beliefs, values, and practices but still promote some level of empowerment among individuals with disabilities. Evidence drawn from the literature as well as professional experience will be used to discuss the relevance and implementation of these respective strategies in terms of their strengths – namely, empowering individuals with disabilities as well as supporting/embracing family, religion, spirituality, and overall cultural diversity.

Key Words: culture, empowerment, diversity

Introduction

There is increasing interest in the relationships between cultural diversity and self-determination as evident in the growing literature (Leake, Black, & Roberts, 2004; Richter, 2007; Trainor, Lindstrom, Simon-Burroughs, Martin, & Sorrells, 2008; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003; Wehmeyer & Schwartz, 1997; Wong-Hernandez & Wong, 2002). Although there have been multiple definitions of self-determination as employed within Western models, the following is commonly cited:

> "Self-determination is considered a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society" (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2).

Self-determination has benefited numerous individuals with disabilities in the West. It has fueled the international Disability Rights Movement resulting in beneficial policies, programs, and services. While practice and research indicates the benefits of certain strategies promoting self-determination in countries such as the United States and other Westernized

countries, these identical approaches and "best practices" are not necessarily proving to be effective in cultures that do not embrace the same values.

Contrasting beliefs and practices regarding self-determination generally involve individualism, competition, future orientation, and self-help (Turnbull and Turnbull, 2001; Zhang, 2005). The importance of "normalization" including independent living and inclusion are not necessarily valued universally (Kim & Morningstar, 2005; Leake, Black, & Roberts, 2004; Richter, 2007; Trainor, 2002). It is the thesis of this paper that culturally appropriate approaches are necessary to engage culturally diverse individuals with disabilities, their families, and their communities to promote the general principles of empowerment, social justice, and rights.

Contributing to this growing concern is an important culturally-related trend emerging in many countries throughout the world, which involves the growth in immigrants, refugees, and cultural minorities over the past several decades. For example, there has been an increased influence of the Hispanic culture in the U.S. as the Latino/Hispanic population has become the largest ethnic minority group (U.S. Bureau of the Census, 2011). Historically, Hispanics in the United States have experienced a proportionally higher rate of disabilities than those identifying as non-Hispanics (U.S. Bureau of the Census, 2000).

Additionally, racial groups such as African Americans and American Indians/Native Americans have held higher disability rates than Caucasians and Asians in the U.S. Concurrently, there has been a disproportionate number of racial, ethnic, and cultural minorities including African American, American Indian, Asian, and Hispanic students identified as students in need of special education (Artiles, Rueda, Salazar, & Higareda, 2005; National Research Council, 2001; Richter, 2007).

In developing culturally appropriate services, it is imperative to consider ethnic and cultural sub-groups. Differences in disability prevalence exist between culture sub-groups. For example, Youngtae (2001) reported that among Asian-Pacific Islanders there is a higher risk of disabilities among Laotians, Hmong, and Cambodians followed by Vietnamese and Pacific Islanders. The failure to differentiate among sub-cultures of any racial or ethnic group is considered "racial lumping" (Sue, 1990; Wong-Hernandez & Wong, 2002). As emphasized by Wong-Hernandez & Wong (2002, p. 102), "If rehabilitation professionals are not sensitive to their consumers' cultural needs and characteristics, the number of clients who achieve below their potential, drop out of programs, or who fail to become rehabilitated and employable will continue to increase dramatically."

Importance of Culturally Tailored Practices

Westernized approaches to promote self-determination cannot necessarily be transplanted into non-Westernized countries. First and foremost, whether and how a society defines and recognizes disability will dictate whether and how they intervene, including the specific service delivery mechanisms they adopt. As indicated by Scheer and Groce, 1988:

> "Universally, societies have explanations for why some individuals (and notothers) are disabled, how individuals with disabilities are to be treated, what roles are appropriate

(and inappropriate) for such individuals and what rights and responsibilities individuals with disability are either entitled to or denied" (p. 38).

Religious explanations, such as committing sin and offending spirits, often blame the disabled for their disability. Punishment often accompanies medical explanations for disability including punishment arising from accidents, alcohol and drug abuse, genetic disorders, infections, and injuries. These explanations serve as the foundation for the various responses of families and communities to individuals with disability. Many cultures that do not view disability as a matter of difference but rather as a handicap do not believe individuals with disabilities can be empowered.

While most world cultures appear to recognize that the environment creates disabling conditions, many individuals experience "powerlessness" and, consequently, do not think change is possible. As indicated in this quote:

> "[Some persons] … have so internalized the general negative attitudes towards them because of their disabilities that they cannot believe that collective action can improve their lives. They have seen the problems as inherent in their medical conditions and have not been urged to join others to demand structural changes that would render the environment useful for them" (Asch, 1986, p.13).

Finally, a significant number of cultures do not necessarily consider the traditional notion of self-determination as relevant especially to individuals with disabilities. One example involves the Japanese culture which places group needs and wants over individual needs and wants (Ritts, 2000 as cited in Brightman, 2005). For many, nuclear families if not extended families are strongly connected, and it is through these family ties that identity, support, and security is established. As indicated by Bremer, Kachgal, & Schoeller (2003), achieving self-determination is not just a matter of acquiring necessary knowledge and skills; it also involves having a conducive environment that is facilitated by key individuals and institutions.

Principles and Strategies Promoting Self-Determination

There are several core principles that characterize self-determination that are not universal across cultures. Individualism is one of these principles, in which primary emphasis is placed on virtues such as self-reliance, individual needs and individual rights (Leake, D. W., Black, R. S., & Roberts, K., 2004). Non-western culture groups may focus less on the individual and more on family through valuing relationships and interdependence (Hall, 1981). This is evident both in the Hispanic culture and among African Americans who have strong family ties which permeate throughout the community.

Another principle and commonly used strategy to promote self-determination in the United States involves independent living and the idea of fostering a least restrictive environment among individuals with disabilities. Again, this runs contrary to the cultural values of non-western groups. For instance, traditional Pacific Island cultures emphasize family life. As supported by McFarlane, Farley, Guerrero, and Galea'i (1996, p.24) "The concept of independent living when described by such terms as empowerment, advocacy, personal choice,

and living independently, goes against Pacific Island cultural practices of respect… family choice and involvement, and living and being with the family."

Alternative Culturally-Based Approaches to Self-Determination

Alternative approaches are being explored and implemented both in non-western countries and among non-western immigrant groups within the West. Two key approaches to reduce dependency and promote self-determination in culturally sensitive ways are (a) to increase the availability and access to culturally diverse resources; and (b) to implement community based rehabilitation (CBR).

Access to Culturally Diverse Resources

Although access to resources is an important element for meeting the needs of individuals with disabilities, access to "valued resources" is a crucial component for empowerment. Lord & Hutchison (1993) describe this distinction:

> "When they experienced powerlessness, most of the participants had access only to resources which they perceived as being different or specifically for "rehabilitation" or "welfare." Beginning to have access to the same valued resources and opportunities as other community members was important for people's empowerment process" (p.14).

Access to culturally relevant valued services are necessary for culturally diverse individuals with disabilities. As recommended by Hampton (2000) in terms of services for AAPIs (Asian American and Pacific Islander) with disabilities, the same may be true for a wide range of cultural groups, i.e., services for culturally diverse individuals with disabilities must match the cultural, linguistic, religious, and psychosocial characteristics of that individual.

One of the most common factors contributing to the underutilization of rehabilitation and mental health services among Hispanic populations is that families serve as their own support services. The notion of actually needing professional services is not desirable. Therefore, Cuban immigrants generally do not seek advice from outside the family even from clergy although they usually have strong religious beliefs in Catholicism (Wong-Hernandez & Wong, 2002).

Similarly, there is a reported pattern of underutilization of social services (including mental health services) among Asians. Chinese immigrants to the United States frequently experience difficulties with counseling styles and approaches (Leong, 1986). Smith and Routel (2010) reported that professionals often develop goals that are incompatible with individual and family beliefs. Hence, many families decide to keep their issues private.

To address these challenges and eliminate barriers, resources must become more culturally relevant and available to the individuals, families, churches, and others that need them. Services must be delivered in a culturally competent manner guided by professionals and para-professionals who are culturally competent. Organizational staff must become knowledgeable of cultural values and norms of their respective community members and receive ongoing training in cultural diversity. At the very least, outreach services should include staff who are bicultural and bilingual to ensure more effective service delivery.

Relevant best practices and/or model programs that focus on delivering culturally competent services should be identified and adopted by all service organizations. This may involve family goal setting, rather than individual goal setting, as part of the self-determination process. Professionals, clients with disabilities, their families, and significant others (who may or may not be familial) should communicate. Networks within communities including partnerships of service organizations, churches, and neighborhood groups should be established. Dissemination of information into the community must be available in native languages, perhaps using audio-visual materials to give "voice" to information.

It is important to note that culture is constantly changing, especially among second and third generation immigrants who may combine their parents' cultures with aspects of their new culture. As a result, this dynamic may actually open the door and facilitate the adoption of new practices. At the same time, the dynamic nature of culture may create difficulties for traditional rehabilitation and social services to keep up with such cultural changes. Already these organizations may be struggling to effectively address the cultural and linguistic needs of diverse clients. This is true of most non-profit entities facing limited and/or diminishing resources themselves. As a result, another alternative strategy may be useful, that of Community Based Rehabilitation.

Community Based Rehabilitation in Culturally Diverse Settings

Over the past several decades, community based rehabilitation (CBR) has been used in developing countries with limited means and resources. CBR is considered "a strategy for enhancing the quality of life of persons with disabilities by improving service delivery, by providing more equitable opportunities, and by promoting and protecting their human rights" (Helander, 1993, p.8).

Community-Based Rehabilitation represents a participatory approach with a focus on assisting individuals with disabilities and their families, while supporting broader community development initiatives. The ideals of CBR echo those of self-determination in the recognition that individuals with disabilities deserve the right to quality of life. However any supports provided are to be compatible with local values and mores, inclusive of natural supports, and made available at low cost.

Evidence has emerged demonstrating the usefulness, effectiveness, and positive outcomes associated with the implementation of CBR in addressing not only the basic needs of individuals with disabilities but also in empowering them in the process (Mitchell, 1999; Wiley-Exley, 2007). Moreover, Community-Based Rehabilitation not only recognizes the role of culture as a common determinant of health, the CBR guidelines emphasize the need to consider cultural factors as an essential element for ensuring sustainability of CBR programs (World Health Organization, 2010):

> "Cultures vary, and what may be culturally appropriate for one group of people may not be the same for another group. To ensure CBR programmes are sustainable in different contexts, it is important to consider how they will affect local customs and traditions, what resistance to the programme may be expected and how this resistance would be managed. It is important to find a balance between changing inaccurate beliefs and

> behaviours related to people with disabilities and adapting programmes and activities to the local context. Community-Based Rehabilitation is becoming increasingly widespread" (p. 37).

As indicated by Bwana & Kyohere (2001), regarding the development of the CBR program, The Association for Spina Bifida and Hydrocephalus (ASBAHU) in Uganda:

> "Even the traditional cultural support system of the extended family seemed unsupportive. Since unity is strength, parents of ASBAHU came together under the old African Philosophy of, *'I am, because we are'*. They chose interdependence over independence."

While many CBR programs have been created through the grassroots organizing of families within communities, there are others that have been initiated in conjunction with religious institutions. One exemplary CBR program is the Karagwe Community Based Rehabilitation Programme (KCBRP) under the Development of the Anglican Diocese of Kagera in Tanzania, East Africa. Organized in partnership with the neighboring Anglican Church of St. Peter, its mission is to "enable the community to provide services with and for people living with disabilities in villages within the Karagwe District." To be successful, KCBRP works with the local government and non-governmental organizations (NGOs) as part of their networking initiative.

It is important to note that self-determination as practiced within the CBR models is not about "independent living", per se, but rather "to the extent that supports are provided to enable that person to retain control over the decision-making process and to participate to the greatest extent in the decision-making or problem-solving process, he or she can be self-determined" (Wehmeyer, 1998, p.10). According to the Center on Self-Determination (2011, p. 1):

> "In order to care for oneself and be an active part of the community, people with disabilities may desire assistance. Each has the right to determine their life goals and what kind of support is needed to achieve them. Those who assist people with disabilities work towards providing access to life opportunities at the highest potential."

Therefore, a community-based approach which relies upon the assistance of natural supports fits well with adhering to the underlying elements of self-determination.

As indicated throughout the literature, "community" is very much a component of the empowerment process. Wallerstein (1992) stated how empowerment is a "social-action process that promotes participation of people, organizations, and communities toward the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice." Even in the United States, culturally diverse groups prefer community supports (especially the church) as opposed to institutionalized care through traditional medical or rehabilitation systems (Leong, Wagner, & Tata, 1995). As described by Wong-Hernandez & Wong (2002):

> "…the Hispanic culture of Cuba views life as a network of personal relationships. The Cuban relies and trusts persons; he or she knows that in times of trouble a close friend or relative can be counted upon for needed assistance. A Cuban relies less on impersonal

> secondary relationships and generally does not trust or place much faith in large organizations. Such as attitude is not unique to Cubans, but rather is typical of most Latin American Societies" (p. 9).

By embracing the notion of Community-Based Rehabilitation, individuals with disabilities are able to become more self-sufficient and contributing within the context of their own community. This creates a more sustainable, effective service delivery system that respects the central place of "family" and other "natural supports" in the life of community.

Conclusion

When supporting culturally diverse individuals with disabilities and their families, it is important to consider cultural factors and to implement culturally-tailored service systems.. Self-determination strategies are more likely to be successful when incorporating family and community into the empowerment process. As stated by Wehmeyer:

> "When the emphasis is not placed on self-determination as independent performance, absolute control, and success, and instead on (a) providing individuals with adequate opportunities to be the causal agent in their lives, make choices, and learn self-determination skills; (b) enabling them to maximally participate in their lives and communities; and (c) ensuring that supports and accommodations are in place, people with significant disabilities can be self-determined" (1998, p. 14).

Implementation of these strategies – namely, empowering individuals with disabilities by supporting/embracing family, community, and overall cultural diversity is imperative in developing effective and sustainable policies and services.

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Technologies for Voice:
Video and Multimedia Communication Supports for Self-Determination

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Abstract: Video and multimedia technologies that support the self-determination of persons with disabilities are explored in a series of three stories. Young adults with disabilities clarify their values, visualize their futures, and speak for themselves, utilizing readily accessible consumer technologies. Professionals and critical friends are challenged to re-tool their technology skills to keep up with people with disabilities who are making decisions that impact their own lives.

Key Words: self-determination, technology, multi-media, video

Introduction

Young people with disabilities are assuming increasing responsibilities for their own goal setting, transitions, and life planning. Self-advocacy includes public expressions of one's hopes and dreams, strengths and assets, support needs, goals, objectives, and career plans (McGahee, Mason, Wallace, & Jones, 2001; Test, Fowler, Brewer, & Wood, 2005). In support of this effort, youth are expected to participate in their own circles of support and to find and share their own voices in the planning process (Agran & Hughes, 2008; Karvonen, Test, Wood, Browder, & Algozzine, 2004; Meadan, Shelden, Apple, & DeGrazia, 2010; Skouge, Kelly, Roberts, Leake, & Stodden, 2007). Regardless of disability, it is the young person, him or herself, who is at the heart of this evolving social value called *self-determination* (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Mason, Field, & Sawilowsky, 2004; McGahee et al., 2001).

Concurrent with the *self-determination* movement is the growing recognition within the American public education system that everyone must acquire video and multimedia communication skills, along with broader technology literacy and skills (NCLB, 2001; PCAST, 1997). In order for a free society to survive, its citizenry must become literate in using the readily available technological tools that support creating, problem-solving, communicating, and decision-making (PCAST, 2011). This movement to re-tool our society stems in part from the recognition that communication now extends beyond merely speaking and writing. Universally-designed information delivery systems, including tools that incorporate visuals, audio, and graphics, enhance communication and provide access to content that previously was unavailable or difficult to access (Ayers & Langone, 2008; Rose & Meyer, 2005). Cross-cultural understanding is enhanced by such technology as it delivers diverse stories, experiences, and perspectives. We call the various multimedia tools that support self-determination and self-advocacy by the phrase *technologies for voice*.

This paper explores the overlap between the two social movements, self-determination and the re-tooling of society, both of which impact youth with disabilities. We share three stories in which young people with disabilities, all of whom are from culturally and linguistically diverse heritages, attained positive outcomes by employing video technologies to clarify values, visualize choices, and communicate those choices with family and critical friends.

We hope to inspire service providers and other critical friends of persons with disabilities to embrace video and multimedia tools of communication and expression. These tools are no longer new. In fact, the young people whom we support have been immersed in commercial media and digital technology since their births. Furthermore, video and multimedia technologies have more recently emerged as tools for self-expression and self-determination within the disability community (Dowrick & Skouge, 2001; Held, Thoma, & Thomas, 2004; Kelly, 2008; Kelly, Skouge, & Thomas, 2005; Lancaster, Schumaker, & Deshler, 2002; Skouge et al., 2007; Wehmeyer et al., 2011). For those of us who support persons with limited communication skills, we are well-advised to become adept at using the emerging technologies for voice. The stories that follow illustrate something of our experience.

Constructing Environments

Bandura (1997) identified three contexts for persons with disabilities. The first and most restrictive context consists of environments without choice (this environment could be exemplified by the commands: "You will live with us. This is the way it is. It is for your own good"). The second context, and the one that is most widely promoted today, offers choices that are typically pre-determined for the person with the disability (e.g., "You will live with us; or you will live with them. You will work here or you will work there"). The third, and potentially the most liberating, context promotes *constructed* environments in which people are challenged to visualize possibilities that are not readily apparent, as in the phrase, "Can we envision a future that realizes your hopes and dreams?"

Constructed environments are the most challenging contexts to actualize, but they are potentially the most rewarding (Dowrick, 1999; Dowrick & Skouge, 2001). Video self-modeling (VSM) strategies utilize a form of constructed environments to support self-advocacy, communication, and learning (Bellini & McConnell, 2010; Delano, 2007; Dowrick, 1999; Mechling, 2005). In VSM, multimedia technology is used to explore strengths, skills, and a vision for the future through carefully edited videos to create positive self-images. Empirical research suggests that when people construct their futures using multimedia, and participate in the processes of planning, rehearsing, producing and reviewing, they are far more likely to realize their goals (Bellini & Akullian, 2007; Hitchcock, Dowrick, & Prater, 2003).

In the three stories that follow, we illustrate simple video techniques to construct environments with young persons with disabilities. Typically, our projects are completed in three meetings: a planning meeting, a day of production and editing, and a gathering of showcase and celebration. Our techniques, however, are secondary to the stories themselves. In our experience, as young people become empowered to speak for themselves utilizing multimedia, the technologies become tools of expression to be employed in a wider variety of ongoing ways.

Story #1: Marcus "This is who I am"

This story is consistent with a growing body of literature suggesting that young persons with disabilities and their families can become active, positive, contributing partners in transition planning. Marcus produced videos of self-expression and presented them at the beginning of his monthly inter-agency meeting. In so doing, Marcus transformed from an insolent resistor of change to a contributing team player.

The authors were employed by the University of Hawai'i to engage youth who had disabilities in video projects to promote self-advocacy and self-determination. Typically, the videos were 8-10 minutes in duration and were intended to be shown at the beginning of planning meetings, in order for parents and professionals to hear the youth's voice first. The youth involved were often considered troubled; they were bouncing through the human services systems, including foster care, mental health, special education and juvenile justice. Our intention was to assist them in becoming enthusiastic, contributing members of their own support teams, instead of passively resisting and barely tolerating the personnel who attended their inter-agency meetings.

Working with Marcus was one of our first assignments. He had a history that included truancy, failure in school, and gang activity. He had recently been involved in an automobile accident which had left him partially paralyzed on one side and slower in speech, and had exacerbated his incorrigibility. Although he was physically self-conscious when we met him, he had begun to reconnect with his peer group and to reengage in risky behaviors. Marcus lived at home, in a rural valley on Oahu.

Although Marcus had been attending his monthly inter-agency meetings, he did so under duress. At the meetings, he spoke little, if at all, while slouching in his chair next to his mother, who looked pained at her son's resistance. The participants talked about Marcus, but not with him. The meetings were expensive to convene. The paperwork was intensive. Everyone believed that Marcus had the potential for a good future. But the process was unsatisfying and discouraging to everyone involved.

Our connecting with Marcus was problematic from the start. Because he was a juvenile, his multitude of services was shrouded in confidentiality. His counselors and therapists were accustomed to delivering services behind closed doors. The idea of inviting two digital storytellers (us) into Marcus's life to support him to produce and direct his own video was a foreign idea. Nonetheless, after some months of wrangling, Marcus's psychologist persuaded the team to give us entrée. Marcus's social worker arranged for us to meet with Marcus at her office. The date was set. We arrived with our tool kit, which included a video camera, a digital still camera, a tape recorder, a mixer and a title maker (note: these days a laptop with editing software would replace the latter two items). Marcus listened to our idea about telling his story, and expressed interest in "producing a movie." We planned to begin the following weekend.

We met Marcus in the front yard of his parents' home, amid chickens and dogs, rusting cars and farm implements. Marcus's father was sitting in a nearby shed. He did not emerge to greet us, nor did Marcus make any effort to introduce us. Marcus wanted to go to a nearby beach, which he called the most beautiful beach in the world, where he had surfed before his accident,

and which he wanted to highlight in his film. We drove to the beach, walked to the edge of the sand, and mounted the camera on a tripod. We showed Marcus how to pan and zoom. He asked to be left alone, so we sat at a nearby table. After about a half hour, Marcus signaled that he was done. On the way home, he shared his excitement that he had caught some "awesome" waves and surfers. We arrived back at the house and left our slippers [sandals] on the porch.

Marcus invited us into his bedroom, which was a tiny spaced filled with a bunk bed, a dresser, a single chair, and a small patch of floor. Clothing was scattered about. There was one small window covered with a tattered curtain. A rotating fan hummed annoyingly. Marcus sat on the lower mattress of the bunk bed, rummaging through piles of cassette tapes trying to locate the perfect music for his video. "It's here," he said. "I just need to find it." It was hot and stuffy. The lights were off. Marcus found the tape, and after much rewinding and fast forwarding, cued it to its beginning. I (Jim) sat in the chair. Mary volunteered to sit on the floor.

The camera rolled. Marcus introduced the song as a "true love song" which he dedicated to his girlfriend. We listened. Marcus rocked on the creaking mattress while cradling the boom box. Reaching under his mattress to retrieve a half smoked cigarette, he lit it with dramatic flair and dragged with a deep inhalation. The song ended. We suppressed the urge to cough. Marcus looked straight into the camera and took another drag. "This is for my parents," he said. "They don't want me smoking, but they know I do. It's how I relax."

"It's how I relax," he exhaled and repeated. The smoke hung heavy in the room. The camera kept rolling. I found myself wondering if I would soon be fired from this job. "What in the world were we doing in this young man's bedroom?"

We spread our editing equipment on the floor. We plugged in our extension cord and power strip, and we worked together to edit the video right then and there, complete with titles, surf images, music, and smoke. Marcus narrated a portion from the beach scene, expressing once again that it was the most beautiful place in the world. The finished VHS tape was named, labeled, and presented to Marcus. We offered to help him produce another when he was ready. Marcus asked for our phone numbers, assuring us that he would be ready to create another video very soon.

As we drove back to town, drained from a day full of activity, I recall thinking how amazing it was that a kid so troubled (and so expensive to society), could be satisfied with taking us to a beach, playing a love song, and smoking a cigarette in front of a camera.

The next day Marcus was on the phone. "This is who I am," he said. "This video is who I am!" We set a date for two weeks hence to produce his next video. This time it was to be a Christmas gift to his family and a piece to be shown at his upcoming transition meeting. Mary went to the mainland to visit relatives. Marcus and I (Jim) were left to make the movie alone.

This time, Marcus had a much different plan. I arrived to find the living room arrayed with photographs on the sofa, chairs, table, and floor. Marcus had raided the family photo albums of their contents and had even removed pictures from their frames on the walls. I gulped as I surveyed the scene: "What will your mother say?" "What if she comes home to this?"

"How will we ever get things back?" "Don't worry," Marcus assured. "She'll love this project." I wanted to believe.

Marcus had a shooting sequence in mind. We recorded each photograph for just 10 or 12 seconds, with Marcus holding up each photo, close to the lens. We had a bit of an assembly line, and the process didn't take more than an hour or so. When we were done, Marcus used a microphone to record commentary about each picture.

He had something loving and positive to say about each of the many people whom we recorded that day, including his parents, brothers and sisters, and the many nephews, nieces, cousins and such. He took great pride in commenting on his family's ethnic diversity, recognizing family members as Pilipino, Chinese, Vietnamese, Hawaiian, and Haole [Caucasian]. "We've got it all," he said.

We added a title and background music. Marcus knew just what he wanted. The photos were returned to their proper places, and by late afternoon when Marcus's mother and sister appeared, we were done. I greeted them; they acknowledged me, perhaps with some suspicion. I expressed how much I had appreciated working with Marcus, and packed the car to leave. I had never been part of a project that was so uplifting. I found myself wondering how a kid with such a bad reputation could express such love and feeling for place and family.

For several months thereafter Marcus would phone to tell me that he watched the videos every day. "That is who I am," he repeated often. "It is who I am." Both videos were shown at his planning meetings. Marcus insisted on showing up a half-hour before the meetings to cue the tape and insure that there would be no glitches. He introduced his work and expected everyone to pay close attention. And, of course, they did. They applauded him. They saw a person totally different from the resistant youth, fidgeting in a chair, who had resented being there.

In the months that followed, the cloak of confidentiality resettled over Marcus's life. Eventually, we lost touch. We can report, however, that the ice was broken within the local mental health establishment as regards video storytelling. Mary and I were supported to continue our work with other youths, one of whose stories was in fact shared publicly at a major mental health conference some months later, representing mental health case workers from across Hawaii.

Story #2: Chef Ryan Makes a Party

In this story, a youth with disabilities and his independent living counselors were challenged to clarify values and see beyond boundaries. The video was initially created to display Ryan's independence as host and chef. Its surprising outcome, however, was to show the value of interdependence and community inclusion.

The first author (Jim) was hired by the Hawai'i Centers on Independent Living to work with their counselors to support consumers to engage in self-advocacy. On the Big Island I met a man with cerebral palsy who enjoyed being with people but spent an uncommon amount of time alone. He lived in a marginally accessible apartment, and was able to independently cruise through his hometown using his electric wheelchair. His sister prepared his meals and brought them to his door at suppertime.

He expressed to us that he would like to learn to cook and host a party for his friends, but his kitchen was too small for him to negotiate. So, he had never acted on the idea. "Let's do it," the counselor and I suggested. "We'll bring adapted kitchen aids and we'll make a party." Ryan was on board. We sat in the living room to formulate a plan. We decided to produce a slide show that would depict Ryan living out his dream.

The next week I returned, camera in hand. We by-passed Ryan's kitchen altogether by running an extension cord to a card table in his front yard, plugging in an electric skillet and a toaster oven, both of which became accessible under these circumstances to Ryan in his wheelchair. We brought the ingredients. Ryan pulled up to the table and went to work. We all helped. I functioned as the photographer, taking digital pictures of every step, carefully framing each shot to display *Ryan as an independent chef.* Photographs included:

- Ryan at the grocery store with his shopping list.
- Ryan pressing meat patties between his hands.
- Ryan slicing tomatoes with the adapted cutting board and knife with "L-grip" handle.
- Ryan frying patties using tongs as grippers.
- Ryan salting fries with the shaker with the adapted handle.
- Ryan serving his friends.
- Ryan and his friends feasting and laughing.

As we set up and photographed the shots, I found myself questioning our rationale. "Why are we doing this? Isn't it false? What do we gain from this?" The reality was that Ryan was not cooking independently. We were helping him every step of the way, just out-of-frame of the camera. There were perhaps 8-10 of us in attendance, including nearly half the independent living counselors in town. Doubts or no doubts, we stuck with the plan.

Later, when the picnic was over, we watched the pictures in Ryan's living room, displayed on his television. We were all laughing. Ryan was always slow to speak, but when the performance was over, with great determination he expressed his truth. "I want to have more parties," he said. "It is fun to work together."

We stayed connected with Ryan throughout the upcoming year. He watched his video many times, and he hosted numerous parties, sharing joy with his friends. What I learned from the experience was a simple lesson that inclusion does not mean "independence." Inclusion means sharing and participating in community.

Story #3: Keoni's "Great Race"

This story brings home a vision to a family. The parents see great joy as their son realizes his dream, as depicted in video, of a single constructed event. They act on it by cutting through red tape and delays to purchase their son an amazing bicycle.

We were asked by several physical and occupational therapists to videotape a physical assessment of a young man who was being evaluated for a tricycle. Keoni was without speech,

and he had severe physical disabilities, including hemiplegia. He was 12 years old and physically large. He refused to walk more than a few yards without sitting to rest. Everyone including his family thought of Keoni as a bit lazy. He loved tricycles however; and his teachers thought a 3-wheeler might motivate him to move and exercise. His family was from Micronesia and struggled to manage in the Hawaii economy. Keoni was too big for a children's tricycle, so efforts were underway to "fit him" for an adult version.

We were invited to produce the video to be sent off island to several therapist trainees so they could evaluate from a distance. The assessment was to occur at a public school, where tricycles of various sizes and styles were available. We arrived at the school at the end of the school day, just at the same time as Keoni and his father. Keoni slowly got out of the car, walking cautiously with braces, holding his father's hand. Keoni did not speak and carried no means of augmentative communication. The resident occupational therapist greeted us with a number of different styles and sizes of tricycles at the ready.

The assessment was conducted. Keoni's range of motion was observed. His strength and stability were measured. He was asked to mount and dismount, pedal and brake. I was doing the filming. Keoni's father, wearing dark glasses, stood off at a distance, uninvolved. Keoni was obviously delighted to see tricycles, but disappointed he was not riding. I (Jim) whispered to a physical therapist friend that this was soooo boring for Keoni: "Ugh." She agreed.

"Hey," I suddenly exclaimed. "Let's film a bicycle race! Let's put Keoni up against the fastest bike racer on Oahu and film a race! We've got the bicycles. We've got the track. All we need to do is recruit some competition!"

And so it happened. A girl about Keoni's size, far too old for tricycles, was innocently walking past the door just as my idea was gaining acceptance. Her name was Marcy. She was heading home from school, a book bag over her shoulder.

"Hey," I said. "We're making a movie of a great bike race. Would you take a few minutes to help us? We need you to race Keoni." "Sure," she said. We were all laughing. We were making a movie!

Keoni's father, always shy and reserved, became animated. He placed his ball cap, in reverse, on top of Keoni's close-shaven head. He slipped his sunglasses onto his son's beaming face. I took out an Alpha Talker and recorded a few quick messages, like "Let the race begin" and "Come on, let's get going" and "Beep, beep. Out of my way." We set up a starting line. Marcy and Keoni were positioned head-to-head, excitement mounting.

I got the camera rolling. Keoni pushed the buttons on the Alpha Talker. "Beep. Beep. Let's get going." A starting signal was sounded. The race was on. Keoni and Marcy were neck-to-neck. Keoni was straining every muscle. This was real. "Go, Marcy, go!" we screamed. "Go, Keoni, go!" we shouted.

Down the parking lot they raced, wheel-to-wheel, inch by inch. Keoni's father trotted beside his son offering words of encouragement in Micronesian language. I, too, ran alongside, camera rolling. Then it ended. Marcy won by a hair. There were high fives and shaka signs [Hawaiian gestures of solidarity]. Keoni took off his glasses and tossed his cap in exuberance.

That evening, I edited a short seven-minute piece, adding music and titles, and delivered it straightaway to Keoni's family. The Big Race, along with the assessment footage, was sent to the therapists and their trainees. Reports were to be written and recommendations to be made. But, before the documents could be produced, we learned that Keoni's family had purchased a beautiful 3-wheeler for their son, entirely on their own. It was a recumbent bicycle they had seen in a catalog. The family had seen all they needed to that day, and they had acted.

Keoni lived for that tricycle. He would sit on it outside their front steps every day after school. He would ride it to the park whenever his parents allowed. One day I filmed him at the park. His family was with him, including his little brother. Keoni pedaled right up to the climbing structure, parked in the sand. He dismounted and indicated to his father that he wanted to climb up to the platform and go down the slide. He did it. The climbing took forever, with his dad pulling from above, and his mom pushing from behind. I filmed it. Keoni did it. A 13-year old boy taking the biggest risk of his life.

Clarifying Values, Asserting Identity, Exploring Inclusion

Perhaps a common thread to these stories is that all of the central actors (Marcus, Ryan and Keoni) were searching for ways to clarify their values, to assert their identities, and to become participating, contributing members of their communities. The videos were constructed to illustrate these themes. In each case, the first audience for each video was the individual and his family. The videos were viewed and reviewed numerous times at home, reemphasizing that his constructed choices were in fact attainable. As Marcus expressed it, "This is who I am!" The second audience for each video was critical friends and professional support teams. The videos enabled Marcus, Ryan, and Keoni to present a "first voice" to the families and teams committed to supporting them. This experience was new for each of them, as each had challenges with oral and written communication.

Re-Tooling Technology Skills

The video technologies employed in this paper are not difficult to learn. It is likely that you or the young people with whom you work are already engaged in digital storytelling in one form or another – often by taking digital photos and showing them on computers, tablets, smart phones, or social media sites (e.g., Facebook). Our presentations are often enhanced with text and music. Some people are even making short videos that are shown on personal television sets and computers or shared more globally on sites such as YouTube. Both digital still cameras and digital video cameras are fairly inexpensive and commonplace. In addition, many phones and mobile devices include these as standard features, and computers even come with free software to edit videos (e.g., iMovie, MovieMaker). All the tools for multimedia expression are now within reach.

If you are new to this, we suggest that you begin by assisting just one person to share a hope or dream. You might start with PowerPoint or some other familiar presentation software. You can share meaningful photographs, add text to explain the significance of the pictures, and add music to set the tone. Or, use a video camera to record important moments that can be shared with others, and perhaps add photographs, text, and music. Then, when the project is complete, encourage your client to be the "first voice" in their planning meeting. It is a start. You will be

entering into new partnership with your client to explore tools for voice and empowerment (Held, et al., 2004).

Honoring Privacy and Confidentiality

Technology can provide change, globalization, and access. The digital stories described in this paper were intended to empower Marcus, Ryan and Keoni to find their own voices for change, for use within their own private and confidential circles (be it within their families or within agencies). For Marcus, who was enmeshed in the social service system, issues of confidentiality almost prevented us from engaging in the project at all. It was easier to obtain media release waivers for Ryan and Keoni, as they had legal guardians who could give consent. In all cases, however, issues of confidentiality and privacy should be considered paramount.

Digital information can now be disseminated almost instantaneously wherever the high-speed Internet is in place, including text, pictures, sound, movies, and "real time" imaging. The opportunities to engage people in creative dialogues are limited only by our imaginations. With these opportunities, however, come our responsibilities: we must counsel and protect the privacy of the clients with whom we partner. For those of us who work for professional agencies, it is likely that legal procedures are in place, requiring the informed consent of the client or guardian to allow information sharing. These legal protections are important, but *they may not be sufficient*.

The implications of the digital revolution are new and beginning to be better understood by us all. For example, the power to record video in our living rooms and broadcast it over the Internet calls for serious consideration. We say and do things differently in the privacy of our homes than in public arenas (even when cameras are recording). We seldom realize that an audience of strangers may see us completely out of context. As professionals, it is essential that we develop and practice techniques to fully inform clients of the possibilities, the risks, and the realities of such digital communications. We should discuss safeguards to privacy, such as reviewing, editing, and deleting digital information before dissemination.

Marcus's and Ryan's videos were gifted to each of them, with the understanding that they owned the material and could share it with audiences of their own choosing. All of the out-takes and original footage were erased. In Keoni's case, the "Great Bicycle Race" has been broadcast on Hawai'i Community Television and throughout the Pacific Basin as part of technology outreach training by this paper's first author. This was accomplished with the enthusiastic support of Keoni and his family.

Finding Voice

Video and other multimedia tools present exciting opportunities for self-determination, self-advocacy, and systems change. Youth are drawn to technology. Now with digital video and still cameras, laptop computers, cellular phones, tablets, and other portable devices, the opportunities are as never before to engage young people in authentic expressions that are anchored in their homes and communities.

As young people find their voices, it is our experience that they do not become rebellious or careless. Instead, they empower and synergize their circles of support to engage in vision-

crafting and problem-solving. Fundamentally, when given a chance, young people want to express gratitude and love to the people who support them. They want to share the beauty of the world as seen through their eyes. They want to live in community, to love and be loved. They want to prepare for a career. And they want to give back. As young people become self-determining, parents and professionals will find their work of guidance and support far more satisfying.

If there is a single lesson from our work, it is that young people with disabilities must own the full process of digital storytelling, from planning their messages, to producing and directing their stories, to editing their final pieces. Finally, they must be fully present at the showing – sharing their voices as natural expressions of who they are, what they want and need, and how they will get there.

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Cultural Beliefs and Attitudes about Disability in East Africa

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Abstract: This interpretive literature review of cultural beliefs and attitudes about disability in East Africa identified themes in four categories including (a) the causes of disability, (b) attitudes towards disability, (c) treatment of people with disabilities, and (d) language about disability. Referencing the medical, social, and pluralistic frameworks for conceptualizing disability, the authors sought to compare and contrast East Africa with perspectives about disability common in the developed world. Implications for policy and practice are discussed.

Key Words: beliefs, East Africa, culture

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The United Nations commemorated 1981 as the Year of Disabled Persons. This event signaled a growing concern about human development and the rights of marginalized peoples throughout the world. The initiatives in *Education for All (EFA)*, originally launched in Jomtien, Thailand in 1990 and renewed in Dakar, Senegal in 2000, have served as a framework for global efforts to improve access to and the equity of primary education (UNESCO, 1994). In 2002, UN Secretary Kofi Annan commissioned the Millennium Project to develop an action plan in order to achieve progress towards the goals of the EFA. These efforts have focused attention on the enormous disparities in educational opportunities across the globe and have provided benchmarks to measure progress towards reducing them. It is clear that in an interconnected, globalized world, we cannot afford to do less than provide educational opportunity to all the world's children (Stromquist, 2006).

Disability issues have become increasingly prominent as one aspect of this movement. A major shift towards inclusive special education worldwide was demonstrated when 92 governments and 25 international organizations signed onto the Salamanca Statement on Principles, Policy, and Practices in Special Education in 1994 (UNESCO, 1994), emphasizing the importance of equity and access to educational opportunities for children with disabilities. In Africa, governments and non-governmental organizations (NGOS) have taken steps to address problems of individuals with disabilities and the African Decade of Disabled Persons (2000-2009) was proclaimed in 2000 by Heads of State and Government meeting at Lomé in 2000. A Plan of Action was adopted at the Pan African Conference on the African Decade of Disabled persons in February 2002 (African Studies Centre Leiden, 2008). Several African countries have passed disability-related legislation in an effort to improve opportunities for individuals with disabilities (Mamboleo, 2011). It is important to note that, while three components of education development (access, equity and quality) are acknowledged as critical to improving education in developing countries, access is often viewed as the lens through which equity and quality are understood. From this perspective, progress is achieved when more children have access to

schools. However, the point is well made that the three components are interdependent (Piper, Dryden-Peterson & Kim, 2006). Further, while the literature on equity in international education focuses mostly on gender equity, there is increasing evidence that improving educational opportunities for individuals with disabilities in the developing world is an important marker of progress in improving educational opportunities for all (Filmer, 2006; Nyerere, 1985; Peters, 2003, 2004).

Within this international context, East African countries present particular challenges. First, these countries face some of the greatest global challenges of our time including disease, environmental degradation, poverty, ethnic conflicts, and human rights abuses. A recent report on progress towards the goals of the Millennium Project indicated that many countries in East Africa are unlikely to reach them by the target date of 2015. Although universal access to primary education has generally increased across the world in recent decades, access rates in this Africa region remain substantially below 100 percent (Piper, Dryden-Peterson, & Kim, 2006). Within this context, equity issues related to the rights of individuals with disabilities to education are not frequently seen as high priority. Yet as Peters (2003) points out, disability may be the single most important factor excluding children from schooling across the world.

It is difficult to establish answers to fundamental questions about disability in East Africa in part because definitions of disability differ considerably across countries and communities. The World Health Organization (WHO) defines disability as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (1980 as quoted in Whyte & Ingstad, 1995, p. 5) and the WHO manual explains that a "[h]andicap depends on valuation and expectations that put the disabled person at a disadvantage" (Whyte & Ingstad, p. 6). It must be acknowledged that these valuations are culturally specific. In East Africa, the functional capacity of an individual to complete life's daily tasks without help are especially salient and may differ dramatically in many respects from the daily life tasks of individuals in the developed world. Under such circumstances, for example, dyslexia may not be viewed as a disability in a community with high illiteracy, whereas someone with a minor physical disability many be quite disadvantaged in a community that requires individuals to walk many miles during the day while carrying needed supplies a great distance (Harknett, 1996). From this perspective, individuals with obvious deformities may be seen as *normal* if they can participate in daily life activities in the community. Similarly, scholars in Africa have noted that an individual not usually identified as *disabled* in the developed world may be considered disabled in many African communities if they cannot participate in important life activities, such as bearing children (Devlieger, 1995; Ingstad, 1995; Zhang, 2001).

Given the difficulties establishing definitions of disability, it is not surprising that incidence figures for disabilities in East Africa vary considerably. WHO estimates that 10% of Africans have a disability, but there is only limited data from African countries as to the actual prevalence (Fujiura, Park, & Rutkowski-Kmitta, 2005). Peters (2003) suggests that the numbers of children with disabilities may be growing due to increasing poverty, armed conflict, child labor practices, violence and abuse, and HIV/AIDS.

Models of Disability

Historically, in developed countries, a medical model of disability has been the cornerstone of special education particularly to determine eligibility for special education services. In the medical model, disability may be viewed "as a defect or sickness which must be cured through medical intervention" (Kaplan, 1999). Individuals with disabilities are diagnosed based on specific characteristics and assigned to a category such as physical disabilities, mental disabilities, or sensory impairments. This perspective assumes that the function of intervention or treatment is to remediate the disability so that the individual will be better able to function within society.

More recently, a social model of disability has been promoted. In this model, disability is viewed as one of many characteristics of an individual that becomes more salient depending on the individual's social interactions. A social model of disability "regards disability as a normal aspect of life, not as a deviance and rejects the notion that persons with disabilities are in some inherent way 'defective'" (Kaplan). As a marker of identity, disability creates a social position for an individual that is constructed in response to widely held notions of normalcy. As Garland-Thomson (1997) explains, "Disability, then, is the attribution of corporeal difference—not so much a property of bodies, as a product of the cultural rules about what bodies should be or do" (p. 6).

Susan Peters (1993a, 1993b, 2004) and others (Ingstad & Whyte, 1995) argue for a merging of models to guide the design of programs and meet the needs of individuals with disabilities within the socio-cultural environment in which they live. Peters (1993a) describes a pluralistic paradigm of disability that acknowledges the importance of socio-cultural beliefs and values in conceptualizing disability. Susan Peters (1993b) also argues that the social model still only provides remediation services for students with disabilities and denies students and families self-determination. Peters prefers to use the pluralistic paradigm where normal functioning is based on local cultural beliefs and values. Socio-cultural studies of disability in the United States and other developed countries have been explored in special education in the developed world (Bogdan & Taylor, 1982; Edgerton, 1979; Haywood, 1970; Skinner & Weisner, 2007; Whyte & Ingstad, 1995) but special education's historical beginnings within science, medicine, and psychology have tended to ground it in a medical model of disability.

For many reasons, cultural beliefs and values play a critical role in the design of educational programs. Clearly beliefs and values influence decisions about curriculum as well as many other aspects of intervention even if the underlying beliefs and values are unexamined. Multicultural education is considered an offshoot of the civil rights movement and was developed in the United States and the United Kingdom as a response to increasing numbers of school children from minority cultures. It has provided much of the rhetoric about the importance of understanding cultural beliefs and values in the developed world as schools are urged to provide content that acknowledges children's cultural identities and teaches children to respect the cultural heritage of others. Both accepting and tolerating cultural diversity and challenging cultural assumptions and stereotypes, two important goals in multicultural education depend on acknowledging and understanding cultural values and beliefs (Banks, Banks, & Banks, 1989; Stromquist, 2006). Cultural beliefs and values also play a critical role in how families and educational programs interact. As parents try to make meaning of their child's disability, they draw on cultural beliefs and values as well as their understanding of normative development for their culture (Skinner & Weisner, 2007). Misunderstanding cultural beliefs may

interfere with family participation in programs whereas understanding beliefs can facilitate trust between families and education programs (Lamorey, 2002).

In an international context, discourse on cultural beliefs and values about disability has influenced services available to people with disabilities across countries and localities (Mallory et al., 1993; Mutua & Dimitrov, 2001; Teferra, 1993). In many developing countries, NGOS including missionary and other donor agencies have dominated the change agenda in education, advocating the need for large-scale changes that would modernize schooling for all children, including those with disabilities (Maclure, 2006; Nyerere, 1985). These large-scale efforts have been criticized for failing to account for local cultural beliefs and values. Others tout the benefits of local programs that privilege indigenous knowledge and favor adapting curricula to meet local cultural contexts and needs (Croft, 2002; Kisanji, 1995b, 1995c, 1995d; Miles, 2002; O'Sullivan, 2002; Stone-MacDonald, 2010).

With the increased emphasis on human rights for people with disabilities, focus has been placed on education and employment opportunities for individuals with disabilities across the globe. Critical to understanding how to support the development of education and employment programs for children with disabilities in developing countries is illuminating views of disability within the cultural context in which the change is to occur. In this literature review, the cultural beliefs and values about disability in East Africa from the scholarly literature are examined in order to understand the perspectives that influence people with disabilities in their daily lives. The intent is to conduct an interpretive analysis examining the literature to find constructs, themes, and patterns that can be used to describe and explain the phenomenon under study (Gall, Gall, & Borg, 2007). The following questions frame the analysis:

(a) How do themes in the scholarly literature describe cultural beliefs and attitudes about disability in East Africa?

(b) How do cultural beliefs and attitudes described in the literature compare or contrast with models of disability in the developed world?

Method

The literature examined was written by authors from and published in North America, Europe, and Africa using the following parameters. First, for the purposes of this review, manuscripts discussing cultural beliefs and values about mental retardation, physical and sensory impairments, and developmental disabilities were included while manuscripts discussing diseases such as HIV/AIDS, cancer, malaria, or leprosy were excluded. Second, East Africa was defined as Somalia, Ethiopia, Eritrea, Tanzania, Kenya, Uganda, Rwanda, and Burundi. These countries were chosen because they represent East Africa according to the United Nations. The countries share similar rural characteristics and a large population that relies on subsistence farming for its livelihood. Tanzania, Uganda, and Kenya share a common language in Kiswahili, and some people in Rwanda and Burundi also speak Kiswahili. All of these countries except Ethiopia were former British colonies. While there are significant cultural differences between and within the countries, this review examines commonalities in cultural beliefs on a topic within this geographical region. Third, the review includes only articles written and published in English. Finally, the earliest entry is from 1982, but there was no chronological limit specifically

set for the literature search. Ninety-five various forms of media including books, journal articles, movies, and government and NGO documents were examined in a larger review about beliefs in all of Sub-Saharan Africa. The current review focuses specifically on journal articles about East Africa.

Using the recommendations provided by McMillan and Schumacher (2006) for qualitative literature review, online databases from anthropology, linguistics, and psychology and special education were searched. Keyword and subject searches used disability, culture, attitudes, beliefs, perceptions, Africa, and East African country names as words. Also, using advanced search functions was intended to identify as many resources as possible. Figure 1 provides a list of the resources consulted. After locating relevant articles, each document was examined and cultural beliefs and values discussed in it were listed. Each entry was coded for statements about culture, beliefs and attitudes, and specific issues related to disability in Africa. After review of the coded documents, categories were developed and representative samples were selected for illustration of each category.

Review of the Literature

The literature reviewed will be presented in four key categories: (a) the causes of disability, (b) attitudes about people with disabilities, (c) treatment of people with disabilities, and (d) and use of language about disability in East Africa. The results are summarized in Table 1.

Beliefs about Cause of Disability

In East Africa, traditional beliefs about the causes of disability continue to be prevalent. Cause is important to consider because beliefs about cause may influence how a person or family is treated. S. G. Harknett classifies beliefs about the causes of disability in three categories: (1) traditional animism includes beliefs that disabilities are punishments for bad deeds or the result of witchcraft exercised by other people. (2) Christian fatalism beliefs revolve around notions that disability results as an act of God's will. (3) Medical determinist beliefs accept the explanations of modern medicine as to the cause of disabilities (1996). It is not uncommon for individuals to use multiple categories of beliefs about cause, perhaps in an effort to neutralize negative beliefs about disability, such as suggesting a medical explanation in addition to traditional animism (Ingstad, 1995).

Taboos and Punishment for Bad Deeds

Beliefs about causes of disability in the examined literature were often described as expressed in proverbs, folktales, oral tradition, and from interviews with traditional healers. Historically, Adams found in 1949 that people in Zimbabwe attributed cerebral palsy to witchcraft, spirits, or disobeying a taboo. They attributed blindness to witchcraft and leprosy to witchcraft, spirits, or natural causes (Mallory, 1993). Mbah-Ndam (1998) explained that disabilities are "regarded as punishment from the gods or bad omens, and hence [people with disabilities] are rejected or abandoned." There are also descriptions of taboos that, when broken, are thought to cause a disability. For example, the Nandi of Kenya consider it wrong to kill animals without good reason during a wife's pregnancy (Ogechi & Ruto, 2002). Having sexual

intercourse during pregnancy is also a taboo, and breaking this too can cause the child to have a disability (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005; Ogechi & Ruto, 2002).

Laughing at people with disabilities could cause an individual to have a child with a disability himself or herself, cause an accident to befall you, or cause future generations in your family to be cursed (Ogechi & Ruto, 2002; Talle, 1995). A study from Kenya reported that family members and health care personnel believed that seizures were caused by several factors including birth trauma, abuse, witchcraft or spirits, and contact with certain animals (El Sharkawy, Newton, & Hartley, 2006).

Misdeeds of family members can also cause a disability. Family members can do something wrong and the family can be punished for the act with a disabled child (Ogechi & Ruto, 2002). In Ethiopia, a father blamed his wife for causing their child's disability after she complained about seeing a person with distorted features in the street (Teferra, 2003). In other cases, when the mistake of the family member is thought to be very bad, a child is born deaf or mute in order to keep them from telling the family secrets (Omiegbe, 2001).

Divine Intervention

God(s) can either bless or curse families who have a child with a disability. In several instances, although disability was accepted as an medical mishap, this explanation was accompanied by the belief that divine intervention caused the accident (Mashiri, 2000). In Tanzania, Kisanji (1995b) found the majority of tribal elders believed that disabilities were caused by God's will (44%) or witchcraft (39%), whereas 82% of classroom teachers believed the disabilities were caused by diseases. In other studies examined, parents of children with disabilities explained that their child was a gift from God or that is was God's will for a child to have a disability (Devlieger, 1999a; Kiyaga & Moores, 2003).

Beliefs are changing and fewer East Africans are described as believing that witchcraft, curses or retribution from God(s) are the sole cause of disability. Medical explanations are more widely accepted. The influences of Christianity and Westernized education and medicine have altered traditional belief. Many report indigenous beliefs (animism) to be archaic (Ogechi & Ruto, 2002). Nevertheless, these beliefs emanate from years of oral tradition and beliefs emanating from traditional religions continue to be described as part of the culture (Omiegbe, 2001).

Attitudes Toward People with Disabilities

Attitudes toward people with disabilities in East Africa have both positive and negative aspects and are often linked to beliefs about the causes of disability. Throughout Africa, it is considered inappropriate to laugh or ridicule people with disabilities (Ogechi & Ruto, 2002; Talle, 1995). In a survey study of families in Kenya in which a family member had epilepsy, family members expressed a range of perspectives. Some believed that individuals with epilepsy could lead a normal life with medication, but others thought their children with epilepsy would not go to school or marry. Overall respondents identified negative attitudes within the community, but also described experiencing support from community members who helped with care and treatment when children had seizures (El Sharkawy, Newton, & Hartley, 2006).

Similarly, Kisanji (1995a) found a range of views when he interviewed Tanzanian tribal elders and schoolteachers about people who were deaf, blind, or had physical or severe disabilities. Some people felt that individuals with disabilities could be productive in society if trained to do certain jobs, while others felt that training people with disabilities was a waste of time and money. In general, teachers gave more positive responses than others (Kisanji, 1995b).

Treatment of People with Disabilities

In many African societies, families and communities care for their children with disabilities, but children and family members appear to be less accepted into the community if the individual cannot contribute economically to the family or the community. Among the Abagusii and Nandi people of Kenya, individuals are described by how well they integrate into social and communal life (Ogechi & Ruto, 2002). As in other East African communities, integration into communal life relates to how well individuals fit within the social norms and, importantly, if they can do their share in the community, whether or not they have a disability as defined by the developed world (Mallory, Charlton, Nicholls, & Marfo, 1993). Furthermore, people with physical, hearing, and visual impairments are not seen as categorically different from others, but simply as people with a specific impairment (Ogechi & Ruto). Similarly, the Maasai of Kenya only see people with disabilities as "abnormal" if they are unable to carry out daily activities (Talle, 1995). This holistic view of people is not uncommon in Africa. Specific characteristics, such as disability appear as less important features than other aspects of an individual (Miles, 2002). Kisanji (1995c) reports that marginalization and the categorization of people with physical disabilities as "subhuman" has been reported in other East African countries, but is not seen in Tanzanian proverbs and oral tradition.

In many East African communities, coming of age ceremonies, marriage, and childbearing involve very important rituals. If people with disabilities are able to take part in these rituals, they are more likely to be accepted. The ability to participate in these rituals increases social standing. Among the Maasai in Kenya, women with a disability can bear children and live in their parents' home, instead of moving into the husband's family home. The children of a woman with a disability will then inherit family property. In fact, this practice of the "girl of the homestead" is a privilege, and is a category not just for women with disabilities, but for other women who remain in their parent's home for a variety of reasons (Talle, 1995).

Some East African communities are reported as demonstrating care for the individuals with disabilities in order to protect the rest of the community. For example, the Chagga of Northern Tanzania believe that people with disabilities satisfy the interests of the evil spirits and if members of the community protect and care for them, evil spirits will not disturb the balance needed for daily life. Caring for individuals with disabilities, therefore, protects members of the community who are not disabled (Mallory et al., 1993). The Turkana of Kenya believe that children with disabilities are gifts from God and the families must care for their children as best they can, or God(s) will take His revenge on the family through death (Kisanji, 1995a).

Families are described as caring for their children, regardless of their condition (Masasa, Irwin-Carruthers, & Faure, 2005). Among the Maasai, all children are cared for the same way, given the same food, and they all participate in the same ceremonies and rituals despite disabilities (Talle, 1995). In Ethiopia, when children go blind, parents help them to maintain

and learn skills that will help them be successful (Teferra, 2003). Benedicte Ingstad recounts a story of a grown man with mental retardation who was hidden away in a locked hut, but upon questioning the family, the researcher learned that he had spent time in an institution at the recommendation of doctors and had developed many problematic behaviors. When the parents requested his release from the institution, it was only granted on the condition that he remained locked up in a hut at all times. After Ingstad gave the mother some advice and encouraged her to socialize the son, he became very friendly and did small jobs around the house and village. This family dearly loved their son and were only doing what they thought was best. They were also following the advice of the trusted professionals who, from certain perspectives, seem to have been misguided (Ingstad, 1995).

People with disabilities in East Africa continue to deal with discrimination that comes about from negative attitudes and beliefs (wa-Mungai, 2009). In Kenya, it is unlawful for people with hearing or visual impairments to become president because the law requires that the president speak and read in Kiswahili and English, not Braille or sign language (Ogechi & Ruto, 2002). In a Ugandan study, caregivers reported discrimination by schools and people in the community. Deaf children are purported to be seen as a burdens to their families and are often hidden to prevent public shame from coming to the family (Kiyaga & Moores, 2003; Stone-MacDonald & Butera, 2011). In a qualitative study from Uganda, some participants did not take their children with disabilities out into the community but cared for them at home. Parents could not enroll their children in school, although they wanted their children to have an education, because the schools had rejected the students or the families could not afford the school fees (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005).

Languages of East Africa

Many East African languages simply do not include words that allow "disabled" to be directly translated from English (Ogechi & Ruto, 2002). Each disability is defined and named as it relates to the body part that does not function normally. East African languages do not provide a common word or construct for "disability," preventing individuals with different disabilities such as physical disabilities, deafness, or intellectual disabilities to be classified together. For example, the Ekegusii of Kenya term a person with an impaired hand "Nyakoboko" and a person with an impaired finger "Nyakiara" (Ogechi & Ruto, 2002). In the Maasai language, there are different words for each of the different common disabilities such as physical impairments and blindness. In Somalia, rehabilitation workers use the term "naafo" in their work, but this term only refers to individuals with amputated or badly injured limbs and does not include those who are deaf or blind (Helander, 1995). Among the Abagusii and Nandi of Kenya, children are often given personal names that describe their disability along with other clan names (Ogechi & Ruto, 2002). Ogechi and Ruto provide examples of names for children with different disabilities that could be nicknames or personal names, such as names for "one who stammers" and "big head," referring to children with speech or mental impairments. In several countries, children are given names that denote their disability (Mashiri, 2000). Parents make choices in the terms they use to describe their children and these may reflect the extent to which they to accept the child and his or her disability. The body and words about the body are prominent in East African languages because a healthy body is important to daily life in local communities (Talle, 1995).

Some words referring to disability are derogatory. For example, when referring to the deaf, the Kinyarwanda of Rwanda use the word "ibiragi" (foolishness) and in Uganda, people use the word "kasiru" (stupidity) (Kiyaga & Moores, 2003). The terms used to describe people with disabilities sometimes derive from categories typically reserved for non-humans (Devlieger, 1998; Mashiri, 2000). Only recently have people in Tanzania started using the term "ulemavu" for disability in general and the terms "asiyeona" and asiyesikia" to refer to an individual who cannot see or one who cannot hear. In Tanzania, the term "watoto wenye ulemavu," meaning children with disabilities is relatively new in daily language (Stone-MacDonald, 2010). These newer terms use person first language and move away from words in the ki-vi noun class that are normally used to reference objects rather than people.

Proverbs are an important form of oral and written communication in East Africa. In many proverbs, kindness towards individuals with disabilities and punishment for negative attitudes or actions are evoked (Devlieger, 1994). Several proverbs describe the punishments for laughing at a person with a disability. Other proverbs from around East Africa indicate that God has placed you on the earth for a reason that should be respected by others. "People with a disability represent life and death and are, therefore, highly ambiguous" (Devlieger, 1999b). According to the author, individuals with disabilities are viewed as a reminder that God controls life, death, and much that happens in between. After extensive research on the use of language as it relates to educational policy, Devlieger recommends the use of proverbs to promote the integration of people with disabilities into communities. Proverbs that express the positive position of people with disabilities in the community should be used to support education and rehabilitation programs and to foster community integration (Devlieger, 1994). He describes how proverbs might be used to "generalize a community's experience and that each proverb [is] accompanied by a parable which provided a sketch of the original situation" (Devlieger, 1999a).

More recently, wa-Mungai (2009) in describing his research in the Kakuma refugee camp in Northern Kenya, comments on the paucity of disability references in proverbs in several East African languages. While the author argues that "it is not in dominant society's interest to come to a full acceptance of the disabled," he also cites examples from popular Kenyan culture in which an individual with a disability is portrayed as successful. The concept of disability, he explains, is clearly in a state of flux, perpetually reworked and "invoked for the service of particular social, cultural, economic and political imperatives."

Discussion

Throughout the reviewed literature about disability in East Africa, a variety of cultural beliefs and attitudes about people with disabilities are illustrated. While the literature suggests variations across different regions and cultural groups in East Africa, specific differences in the treatment of individuals with disabilities among various cultural groups are difficult to ascertain. Although clearly disadvantaged by a lack of resources to address social and educational needs, a variety of responses to disability is common. In this regard, East Africa does not differ from the nations of the developed world. Some authors report that individuals with disabilities are well cared for, generally integrated into the community, and that services to help them are provided when available. In other instances, authors report that individuals with disabilities in East African countries are ridiculed and denied services in favor of people believed to be more economically productive.

The literature about disabilities in East Africa also demonstrates culturally specific attitudes and beliefs that suggest a social or pluralistic model of disability is more common in East Africa than in the developed world. First, a range of beliefs about the causes of disability is evident. While most authors document a growing awareness of the biological or genetic causes of disability, witchcraft, the breaking of taboos, punishment by God(s), indication of God(s) will or God(s) giving the child as a gift continued to be reported as an important aspect of how East Africans understand disability. Second, based on the literature reviewed, it appears that individuals with disabilities are less likely to experience stigma associated with an obvious physical deformity or a diagnostic label and more likely to face discrimination if they are unable to participate in the daily social and economic activities of the community than their counterparts in the developed world. While the range of beliefs about the causes of disabilities may seem archaic from the perspective of the developed world, it is noteworthy that the social-cultural context in which disability as an event occurs appears as a critical feature of how disability itself is understood in the East African context.

It is also evident in the literature that East Africans have a more holistic view of well-being or "wholeness" than is typical in the developed world (Harknett, 1996). The reviewed literature demonstrates that East Africans are less likely to view disability as an isolated construct than individuals in the developed world. This holistic view is evident when the language used to refer to disability is examined. Specific references tend to be more often directly descriptive of characteristic appearance or the function (or lack) of various body parts. The study of East African proverbs serves to provide additional understanding about the attitudes and treatment of individuals with disabilities in East Africa and suggests that the socio-cultural context is central to understanding how disability is understood. It is of note that only recently have some East African languages had words to describe individuals with disabilities as a group. Considering the array of terms and acronyms associated with various disability categories and diagnoses in the developed world, the contrast with the developed world in this instance is pronounced.

Given that a social or pluralistic model of disability is more common in East Africa, it would be easy to conclude that individuals with disabilities are more fully included in East African schools and communities. In some situations this may indeed be the case. The literature provides examples of how individuals with disabilities in East Africa are relatively well assimilated into the community. This may be more common in some rural East African communities where traditional communal social organization is more apparent (Ogechi & Ruto, 2002; Stone-MacDonald, 2010).

Overall, however, there is more compelling evidence that individuals with disabilities in East Africa continue to be excluded from schools and opportunities for work, virtually ensuring that they will be live as the poorest of the poor, forced to resort to begging as a means of survival. This is of grave concern as rural to urban migration across the globe continues. A 2008 United Nations report predicts that about 80 percent of the world's population growth to 2050 will be in urban areas in Asia and Africa. Under such circumstances, considerable strain is placed on educational services including public education (Spring, 2009) and efforts to meet the needs of individuals with disabilities may be even less likely to be prioritized. If individuals with disabilities were indeed well assimilated into African communities in the past, it appears likely that the disruption that accompanies urban migration will disrupt it. Under such conditions,

unless focus continues on protecting the rights of individuals with disabilities in East Africa, Ogechi and Ruto's (2002) statement that "[t]he positive indigenous treatment of the disabled is now fast eroding away" (p. 64) will continue.

The literature reviewed is replete with examples of the importance of greater understanding of local culture and beliefs by NGOs and other agencies from the developed world as they collaborate with communities in East Africa on behalf of individuals with disabilities. Collaboration with local stakeholders in planning and implementing education and rehabilitation programs is described as essential. Clearly, in order to effectively respond to the increasingly urgent needs of individuals with disabilities in East Africa, it is critical to acknowledge multiple ways of seeing and knowing the world. As Paul Wangoola, the founder of Mpambo, The African Multiversity in Uganda explains, "problems of human kind today cannot be resolved by modern scientific knowledge alone, or by indigenous knowledge alone. More durable solutions will be found in new synthesis between indigenous knowledges and modern scientific knowledge" (as quoted in Spring 2009, p. 145). Increasingly, East African scholars advocate for this perspective about disabilities. For example, Teferra (2003) promotes holistic programs that view the whole child within their family and community. This approach supports the needs of the family and the community as well as the individual. The author insists that dialogue can increasingly sensitize key stakeholders to the needs of individuals with disabilities and their families particularly when the discussion acknowledges and builds upon indigenous knowledge in a thoughtful and respectful manner.

Finally, it is important to note the importance of research that can serve to illuminate understanding of cultural beliefs and attitudes about disability in East Africa and elsewhere. It is likewise important to acknowledge that, given the enormous geographic, linguistic and demographic diversity involved in such undertakings, this as a vastly presumptive task particularly from the perspective of the developed world. Moreover, as Maclure (2006) points out, African educational research is heavily dependent on foreign funding making it difficult to ensure that the process and products that emanate from it are truly reflective of the sociocultural context in which they originate. Nevertheless, if the goal is to support people with disabilities within their families and communities and cultural knowledge is to be the foundation for developing interventions (Devlieger, 1999b) we must understand and take into account the cultural attitudes and beliefs in which they reside. Research can help us acquire the needed understanding.

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Figure 1. List of Databases Consulted

Academic Search (EBSCO)
African Journals Online
African Studies (Biblioline Quick Search)
African Studies Companion
Anthropological Index Online
Anthropology Plus
Bibliography of Africana Periodical Literature Database
Center for Research Libraries
Current Bibliography on African Affairs (2002-2006)
Dissertations and Theses Abstracts
ERIC
IUCAT (Indiana University Library Catalog)
JSTOR
Linguistics and Language Behavioral Abstracts
MLA International Bibliography
PAIS International
PsychINFO
Quarterly Index of African Periodical Literature
Theses Canada
Web of Science
WorldCAT

Table 1. Summary of Key Categories

Categories	Articles	Country
Taboos and Punishment for Bad Deeds	Mallory et al. (1993)	Various Countries
	Talle (1995)	Kenya
	Mbah-Ndam (1998)	Various Countries
	Ogechi & Ruto (2002)	Kenya
	Kiyaga & Moores (2003)	Various Countries
	Hartley et. al (2005)	Uganda
	El Sharkawy et. al (2006)	Kenya
Blaming Individuals	Talle (1995)	Kenya
	Mashiri (2000)	Kenya
	Omiegbe (2001)	Various Countries
	Ogechi & Ruto (2002)	Kenya
	Teferra (2003)	Ethiopia
Divine Intervention	Mallory et al. (1993)	Various Countries
	Kisanji (1995b)	Tanzania
	Devlieger (1999a)	Various Countries
	Mashiri (2000)	Kenya
	Omiegbe (2001)	Various Countries
	Kiyaga & Moores (2003)	Various Countries
Attitudes Toward People with Disabilities	Kisanji (1995b)	Tanzania
	Talle (1995)	Kenya
	Deku (2002)	Various Countries
	Ogechi & Ruto (2002)	Kenya
	Kiyaga & Moores (2003)	Various Countries
	El Sharkawy et. al (2006)	Kenya
Treatment of People with Disabilities	Mallory et al. (1993)	Various Countries
	Devlieger (1995)	Various Countries
	Ingstad (1995)	Various Countries
	Kisanji (1995b)	Various, Tanzania
	Talle (1995)	Kenya
	Miles (2002)	East African countries
	Ogechi & Ruto (2002)	Kenya
	Teferra (2003)	Ethiopia
Language Differences	Helander (1995)	Somalia
	Talle (1995)	Kenya
	Devlieger (1998)	Various Countries
	Devlieger (1999a)	Various Countries
	Ogechi & Ruto (2002)	Kenya
	Kiyaga & Moores (2003)	Various Countries
	Stone-MacDonald (2010)	Tanzania

BOOK & MEDIA REVIEWS

Book Review

Title: *The Politics of Neurodiversity: Why Public Policy Matters*

Author: Dana Lee Baker

Paper: Boulder, CO: Lynne Rienner Publishers

Hardcover: ISBN 978-1-58826-754-2

Cost: $55.00

Reviewer: Mark F. Romoser, B.A.

Neurodiversity is the notion that neurological differences, like other disabilities, may be seen as differences, not disease. It has become a popular buzzword of late, particularly as it applies to the autism spectrum. Dana Lee Baker of Washington State University-Vancouver attempts to address the policy issues surrounding neurodiversity in this volume.

The book opens with a description of the heated controversy surrounding President Obama's nomination of Ari Ne'eman, an outspoken advocate for neurodiversity and himself an Autistic person, to the National Council on Disability. Unusually for such a relatively low-profile nomination, a Senator placed Ne'eman's nomination on anonymous hold. Bitter opposition to Ne'eman's nomination came from, among others, Autism Speaks, a wealthy and powerful organization that views autism as a "devastating" illness, seeks to find a cure for it, and objects strenuously to Ne'eman's belief that it is perfectly natural to be an Autistic person.

Ultimately, the hold was dropped, Ne'eman's nomination was approved, and the book moves on. After the initial fireworks, it settles into a sober discussion of the tension between four types of advocacy: cause, care, cure and celebration. The author tries so hard to remain neutral that it is difficult for her to address the conflicts between these in any meaningful way. Some measure of the awkwardness of this construct may be gained from her placement of Special Olympics, which is viewed by many self-advocates as patronizing, in the "celebration" category (p. 125).

Baker does, at least, mention aspects of Autistic culture such as Autreat, an annual retreat that has been going on for about the last twenty years. There, "neurotypicals" (people without Autism) are expected to conform to Autistic social norms, rather than *vice versa*. Also, she employs the recent film *Autism: The Musical*, which features a number of Autistic children from across the spectrum, as the starting point for a discussion of inclusion of people considered lower-functioning within the neurodiversity movement.

Baker makes extensive use of her Canadian background to compare and contrast the direction of the neurodiversity movement in Canada versus the U.S. For instance, most U.S. readers will be unfamiliar with the *Auton* case, in which a group of parent advocates sued to force the government of British Columbia to pay for expensive applied behavior analysis (ABA) treatment – and were opposed by Autistic self-advocates, who felt that Autistic children should not be subjected to such rigorous treatment designed to "cure" them against their will.

Overall, this volume represents the beginning of a much-needed discussion about the issues raised by the emergence of the neurodiversity movement – but by no means is it the last word.

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Book Review

Title: *Words in My Hands: A Teacher, a Deaf-Blind Man, an Unforgettable Journey*

Author: Diane Chambers

Publisher: Ellexa Press, Conifer, CO, 2005

Paper: ISBN: 9760967-0-6

Cost: $15.95**,** 263 pages

Reviewer: Yevgeniy Tethukhin

An entirely new world opened to me when I got to know the people portrayed in this book, the world where willpower prevails over the physical possibility (or rather impossibility), the world of super challenges and the world in which people never say die.

Sometimes (or perhaps very often) there happen to be moments in everybody's life when a person seems to come to his limits, when he/she seems to be ruined by desperate failures and frustrations. And if this person, in addition to his mental troubles, is physically disadvantaged, then there comes the time for a choice, for weighing all pros and cons, for considering all good and bad sides in the endeavor to find a possible equilibrium for further existence. And sometimes it may happen so that the negative part of the life can prevail and can come dominating over you and would demand an immediate choice from you so urgently, that you can hardly breathe, that you seem completely disoriented and lost…And here would come such characters, such people , such heroes as pictured in this book, and they will give you a warm welcoming hand through the darkness of desperation and would cast a majestic light onto your life road. And you will suddenly understand where to go and what to do as you are enlightened by their desire to live, to enjoy life no matter how hard it can be.

These are the thoughts that came to me when I read this book, as I read it not with my eyes, but with my heart. I do not see the words and decipher their meaning. I see the real life, I feel the burning heart beating extending its influence far beyond the limits of words. And I feel the same that Burt–the main hero felt, I am groping in darkness together with him when he is trying to get through his physical disability, I am growing with him, and I begin to breathe new air–the air of real freedom and independence, which makes me see what was hidden from me as I saw things as they appear before my eyes but I could not see things which were secretly hidden in hearts and minds of people.

Yevgeniy Tetyukhin, Kandidat of Philology Sciences, is an Associate Professor of Linguistics at North Kazakhstan State University and an international wheelchair racer, and two-time Paralympian. He may be contacted at yevgeniy.tetyukhin@gmail.com

DISABILITY STUDIES DISSERTATION ABSTRACTS

Disability Studies Dissertation Abstracts

Editor's Note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at http://www.hsls.pitt.edu/guides/histmed/dissertations/

Reframing narratives and reevaluating bodies: Incorporating disability into narratives.
Johnson, Katyna. Proquest Dissertations And Theses 2009. Section 0142, Part 0316 226 pages; [Ph.D. dissertation].United States – New Mexico: The University of New Mexico; 2009. Publication Number: AAT 3368070.

Homebound instruction: The legal segregation of students with disabilities under the Individuals with Disabilities Education Act.
Lustig, Benjamin Craig. Proquest Dissertations And Theses 2009. Section 0096, Part 0514 193 pages; [Ph.D. dissertation].United States -- Iowa: The University of Iowa; 2009. Publication Number: AAT 3373920.

Teachers' willingness to provide accommodations for students with bipolar disorder.
Tarbox, Jennifer Anne. Proquest Dissertations And Theses 2009. Section 0010, Part 0525 146 pages; [Ph.D. dissertation].United States -- Arizona: Arizona State University; 2009. Publication Number: AAT 3371240.

Influences during student teaching on preservice teachers' attitudes toward the inclusion of students with disabilities in the general education classroom.
Huber, Jennifer J. Proquest Dissertations And Theses 2009. Section 0050, Part 0529 294 pages; [Ph.D. dissertation].United States -- South Carolina: Clemson University; 2009. Publication Number: AAT 3369259.

Improving the writing performance of high school students with Attention Deficit/Hyperactivity Disorder and writing difficulties.
Jacobson, Laura Thompson. Proquest Dissertations And Theses 2009. Section 0138, Part 0529 127 pages; [Ed.D. dissertation].United States -- Nebraska: The University of Nebraska - Lincoln; 2009. Publication Number: AAT 3369352.

Effects of two intervention approaches on Korean general and special education teachers' goals, attitudes, factors affecting willingness to teach, and knowledge regarding sexuality education for students with intellectual disabilities.
Kim, Hye-Jin. Proquest Dissertations And Theses 2009. Section 0054, Part 0529 204 pages; [Ph.D. dissertation].United States -- New York: Columbia University; 2009. Publication Number: AAT 3373772.

A chaotic companion: Writers and writing with bipolar disorder.

DiPaula, Lauren Teresa. Proquest Dissertations And Theses 2009. Section 0318, Part 0681 290 pages; [Ph.D. dissertation].United States -- Pennsylvania: Indiana University of Pennsylvania; 2009. Publication Number: AAT 3369972.

Confronting "the stare": Women with dis/abilities, negative cultural representations, and resistance.
Schaller, Janet Ellen. Proquest Dissertations And Theses 2004. Section 0231, Part 0319 274 pages; [Ph.D. dissertation].United States -- California: Claremont School of Theology; 2004. Publication Number: AAT 3373838.

The prevalence of ADHD symptoms in a culturally diverse and developing country, Lebanon.
Bathiche, Marie. Proquest Dissertations And Theses 2008. Section 0781, Part 0622 225 pages; [Ph.D. dissertation].Canada: McGill University (Canada); 2008. Publication Number: AAT NR50775.

Antecedents and outcomes of workplace discrimination as perceived by employees with disabilities.
Bradley, Jessica Lynn. Proquest Dissertations And Theses 2009. Section 0050, Part 0624 138 pages; [Ph.D. dissertation].United States -- South Carolina: Clemson University; 2009. Publication Number: AAT 3369243.

Organizational decision making relative to employees with disabilities: Evidence of shifting standards.
Lynch, Joel Edward. Proquest Dissertations And Theses 2009. Section 0162, Part 0624 259 pages; [Ph.D. dissertation].United States -- Illinois: Northern Illinois University; 2009. Publication Number: AAT 3369793.

The new American grotesque: Freaks and other monstrous and extraordinary bodies.
Raphael, Raphael. Proquest Dissertations And Theses 2009. Section 0171, Part 0900 280 pages; [Ph.D. dissertation].United States -- Oregon: University of Oregon; 2009. Publication Number: AAT 3377393.

Narrating lives and raising consciousness through dance: The performance of (dis)ability at Dancing Wheels.
Quinlan, Margaret M.. Proquest Dissertations And Theses 2009. Section 0167, Part 0378 486 pages; [Ph.D. dissertation].United States -- Ohio: Ohio University; 2009. Publication Number: AAT 3371581.

Teachers' perspectives and attitudes towards integrating students with learning disabilities in regular Saudi public schools.
Al-Ahmadi, Nsreen A.. Proquest Dissertations And Theses 2009. Section 0167, Part 0529 367 pages; [Ph.D. dissertation].United States -- Ohio: Ohio University; 2009. Publication Number: AAT 3371476.

A qualitative investigation of ASL/English bilingual instruction of deaf students in secondary science classrooms.

Lane-Outlaw, Susan L.. Proquest Dissertations And Theses 2009. Section 0505, Part 0529 208 pages; [Ph.D. dissertation].United States -- District of Columbia: Gallaudet University; 2009. Publication Number: AAT 3376998.

Making way through the borderlands: Latino youth with disabilities in transition from school to adult life.
Povenmire-Kirk, Tiana Cadye. Proquest Dissertations And Theses 2009. Section 0171, Part 0529 141 pages; [Ph.D. dissertation].United States -- Oregon: University of Oregon; 2009. Publication Number: AAT 3377392.

Characteristics of highly effective teachers: A perspective from students with disabilities.
Smith, David J.. Proquest Dissertations And Theses 2009. Section 0743, Part 0529 131 pages; [Ed.D. dissertation].United States -- Iowa: University of Northern Iowa; 2009. Publication Number: AAT 3375239.

Attitudes of older adults toward their peers with mental disabilities.
Goatcher, Sandra Margaret. Proquest Dissertations And Theses 2000. Section 0303, Part 0351 200 pages; [M.Sc. dissertation].Canada: The University of Manitoba (Canada); 2000. Publication Number: AAT MQ53160.

The influence of empowerment on recovery in psychiatric treatment: An exploratory study of therapeutic relationships.
Saruwatari, Toshiaki Donald. Proquest Dissertations And Theses 2009. Section 1351, Part 0347 121 pages; [Ph.D. dissertation].United States -- Minnesota: Capella University; 2009. Publication Number: AAT 3371726.

Contentment in "Songs of the Gorilla Nation: My Journey through Autism": A humanbecoming hermeneutic study.
Bonis, Susan A.. Proquest Dissertations And Theses 2009. Section 0118, Part 0569 174 pages; [Ph.D. dissertation].United States -- Massachusetts: University of Massachusetts Amherst; 2009. Publication Number: AAT 3372255.

The lived experience of feeling misunderstood for persons living with vitiligo.
Condon, Barbara Backer. Proquest Dissertations And Theses 2008. Section 0205, Part 0569 197 pages; [Ph.D. dissertation].United States -- South Dakota: South Dakota State University; 2008. Publication Number: AAT 3371540.

Exploring attitudes toward people who stutter: A mixed model approach.
Hughes, Stephanie. Proquest Dissertations And Theses 2008. Section 0018, Part 0460 328 pages; [Ph.D. dissertation].United States -- Ohio: Bowling Green State University; 2008. Publication Number: AAT 3375050.

Cultural differences in the experience of the assessment, diagnosis, and treatment of ADHD in a son: Interviews with three Mexican and three Caucasian American mothers.

Chavarela, Susan. Proquest Dissertations And Theses 2009. Section 1434, Part 0622 195 pages; [Psy.D. dissertation].United States -- California: Alliant International University, San Francisco Bay; 2009. Publication Number: AAT 3377439.

Career development experiences of Asian Americans with chronic mental health disabilities. Ng, Vicky Yik-Yi. Proquest Dissertations And Theses 2009. Section 0072, Part 0603 157 pages; [Ph.D. dissertation].United States -- New York: Fordham University; 2009. Publication Number: AAT 3373830.

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The mission of the Center on Disability Studies (CDS), at the University of Hawai‘i at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai‘i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai‘i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai‘i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai‘i, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.